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Annotated Bibliography on Consumer-Operated Services

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This annotated bibliography is based on a review of 59 articles about mental health consumer/survivor self-help groups and organized consumer-operated services. Both published and unpublished manuscripts, reports, and papers are included. This literature overwhelmingly supports the value of consumer/survivor involvement at all levels of the mental health delivery system, whether the consumers/survivors are working as peer-specialists in mental health centers, developing and participating in research, administering consumer-run services at independent or alternative programs, or delivering case management services within a team of professionals. Programs fall into four basic models of peer-support: drop-in centers, educational programs, peer-support groups, and peers as staff within a traditional mental health system. Consumer/survivor peer support services and programs grew out of both the patients' rights movement, a civil rights movement against involuntary commitment and forced treatment, and the general self-help movement in the United States. Consumer-operated services and peer-support promote the empowerment and self-determination of consumers/survivors, and continue to grow and develop in the United States and throughout the world.

Main points from material annotated in this bibliography include:

1. Support given by consumers/survivors tends to be more mutual and less hierarchical than support given by mental health professionals.
2. Empowerment of mental health consumers/survivors is critical in the consumer/survivor movement and works on a social level to eliminate stigma and discrimination, and on an individual level to support recovery.
3. Peer-led self-help groups have positive value as an adjunct to psychiatric care.
4. Self-help groups help to meet the increasing demands for mental health services.
5. Self-help groups need to maintain some autonomy from the mental health system.
6. Whether a consumer/survivor continues to attend a self-help group may be most influenced by the fit between the member and the group.
7. Online services are one effective way to access self-help.
8. Self-help groups are a growing social movement because they are responding to otherwise unmet needs of consumers/survivors.
9. Peer support services go beyond personal mental health issues to address poverty, racial tension, class issues, sexism, homophobia, and other forms of discrimination.
10. Self-help groups need to become more sensitive to the needs of culturally diverse populations, such as Latinos, African-Americans, and Gays/Lesbians.
11. Outreach to the African-American population in the area of self-help is important because African-Americans use these services at a disproportionately low level.
12. With the exception of people with substance abuse problems, women are more likely than men to seek self-help support.

13. Self-help and other consumer/survivor-driven services are cost-effective, but consumers/survivors need to be fairly compensated for the work they do. The literature advocates for equal pay and benefits for consumers/survivors.
14. The literature advocates for collaboration between consumers/survivors and professionals in the delivery of clinical and social support programs.
15. Consumers/survivors have much to contribute in terms of empathy, street smarts, encouragement of peers, role modeling, fighting stigma, and educating mental health professionals and researchers.
16. Because of their street smarts, systems knowledge, flexibility and patience, consumers/survivors are in a unique position to serve individuals who are both homeless and have a mental disability.
17. How to set boundaries between consumer/survivor case managers and their clients needs further exploration.
18. Consumer/survivor case management teams provide more effective case management than mental health professional teams without consumers/survivors as members.
19. There needs to be more evaluative research of consumer-run programs.
20. In order to understand how peer-support services work and for whom, alternative research methods--such as ecological, participatory, and narrative research--are needed, as are quantitative research designs and methods of assessment.
21. Consumers/survivors need to be involved in all phases of research on consumer-operated services, including the management, development, implementation, and interpretation of research projects.

Armstrong, M. L., Korba, A. M., and Emard R. (1995). Of mutual benefit: The reciprocal relationship between consumer volunteers and the clients they serve. Psychiatric Rehabilitation Journal, 19 (2), 45-49.

The Community Progress Service (CPS) was developed in 1986 by the Canadian Mental Health Association (CMHA) to increase the quality of life of individuals with psychiatric disabilities living in board and care homes. This report describes the (CPS) consumer volunteer program and presents the results of an evaluation of the program. The program was developed to integrate consumers in service delivery and provide some components of case management to individuals on the case management waiting list. CPS matched individuals with psychiatric disabilities (clients) one-to-one with other individuals with psychiatric disabilities who were further along in their recovery (volunteers). Although volunteers were not paid, they were given a monthly allowance to use as they saw fit. The program was coordinated by a person with a psychiatric disability.

Volunteers and clients were interviewed by a volunteer in another program. Anonymity was guaranteed. Sixteen active members were interviewed. Volunteers found that regularly discussing things in the Peer Support Network group was the most valuable part of the program. Few commonalities existed when volunteers were asked about the most difficult aspect of their job. However, all volunteers agreed that the most rewarding experience was seeing their partner enjoying the contact. Eleven of 12 volunteers indicated that they would continue to participate despite the lack of payment, even though the lack of payment was a negative aspect of the work. Volunteers and clients rated the types of interaction they had with each other. No significant differences were found between volunteers and clients. Both groups rated providing support and encouragement and talking about problems, feelings, and concerns as most

important. Most did not want to spend time talking about how to cope with their disability or specific aspects of it. An acceptance of each other seemed to exist because volunteers and clients shared a disability. Likewise, more empathy seemed to grow out of this volunteer and client commonality. Volunteers and clients seemed to benefit equally in terms of quality of life, personal development, activity levels, and sense of identity. Because of these benefits, the program was viewed as effective.

Budd, S. (1987). Support groups. In Budd, S., Harp, H. T., and Zinman, S. (eds). Reaching across: Mental health clients helping each other. Riverside, CA: California Network of Mental Health Clients.

Budd explains how support given by professionals is different from support given by peers. The latter is voluntary and not based on a hierarchy. Peers learn independence and develop our own power. The goal of support is not therapy but rather shared knowledge, caring, and encouragement. Budd warns against treating peers in the ways a therapist might, and outlines 10 things a support group can do. They include outreach, helping with income benefits, providing crisis response, providing psychosocial rehabilitation, providing supportive services of indefinite duration, providing adequate medical and mental health care, providing back-up support to family, friends, and community members, involving concerned community members, protecting client rights, and providing case management services.

Also discussed are things a support group cannot do. For example, giving support to family members directly is difficult because they do not necessarily trust our judgement. Our best mode of supporting families is to support the peers. Budd briefly discusses group rules, encouraging groups to keep them few and simple. Confidentiality is discussed at length and a foundation of dos and don'ts is offered for mutual support groups. Last but not least, Budd provides a lengthy list of pitfalls to avoid in the areas of leadership-membership and support, and three helpful questions to ask ourselves when giving support.

Budd, S., Harp, H. T., and Zinman, S. (1987). Reaching across: Mental health clients helping each other. Riverside, CA: California Network of Mental Health Clients.

This 238-page manual describes mental health consumer-controlled, self-help group issues. Twenty-four chapters are written by mental health consumers who have been involved in starting self-help groups. A glossary of much-used references and a 31-page guide to self-help groups are included.

Chapters 1-3 deal with definition and philosophy. Chapters 4-7 deal with setting up groups and providing a supportive environment. These sections are followed by four chapters discussing outreach to members, to the community, and to funding sources. Organizational structures and processes are covered by Chapters 12-17. Special activities, such as newsletters and conferences, are discussed in three more chapters. Finally, Chapters 21- 24 discuss challenges facing self-help groups, and offer possible solutions.

Chamberlin, J. (1988). On our own: Patient-controlled alternatives to the mental health system. England: MIND.

This book is written from the ex-patient's point of view and takes a look at psychiatry and alternatives to it. The book was published in the decade of the

mental patients' liberation movement, when involuntary commitment affected all aspects of mental health care. Chamberlin discusses the overwhelming isolation and contempt most treatment imposed at the time. This book includes many personal anecdotes. Chamberlin makes a case for patient-controlled mental health services, which would be a real alternative to institutions that destroy people's lives.

The book includes nine chapters and an appendix listing United Kingdom groups run by patients and ex-patients. Chamberlin's ex-patient's point of view is clear in the titles of her chapters: "The Patient's View of the Mental Health System"; "The Making -- and Unmaking -- of a Mental Patient"; "Consciousness-Raising: Alternatives and False Alternatives"; "When People Go Crazy: Inside the Mental Patients' Association"; "Money -- and Other Practical Problems"; "Coercion or Co-operation?"; and finally "People, Not Patients," which seems to be the point of it all.

Chamberlin, J. (1997). A working definition of empowerment. Psychiatric Rehabilitation Journal, 20, 43-46.

According to Chamberlin, "empowerment" has become a popular term in mental health programs, yet it has lacked a clear definition. In a research project designed to measure empowerment in programs run by and for mental health service users, Chamberlin first attempted to develop a working definition of the term. Key elements of empowerment were identified, including access to information, ability to make choices, assertiveness, and self-esteem. Chamberlin's empowerment has both an individual and a group dimension. Details of the definition are provided, along with a discussion of the implications of empowerment for psychiatric rehabilitation programs.

A group of 12 leading U. S. consumer/survivor self-help practitioners formed the Advisory Board of the Center for Psychiatric Rehabilitation's research project. After much discussion, empowerment was defined as including at least 15 elements, such as having decision-making power and coming out of the closet. According to the Board, empowerment describes a process rather than an event. The article discusses each of these elements briefly. Chamberlin describes the research project, i.e. to define empowerment, as a starting point for developing a measurement instrument.

Chamberlin, J. (1995). Rehabilitating ourselves: The psychiatric survivor movement. International Journal of Mental Health, 24, 39-46.

When the author first became involved in the patients' rights movement, it was a small and unfunded civil rights movement. People joined because they wanted a voice in organizing to fight the system that had taken away their power. At the same time, the movement developed an innovative form of self-help/mutual-support services. Chamberlin briefly tells her story. She indicates that the key issue is forced treatment, which makes patients feel even more out of control. She writes about being the good patient while inside resisting. Until professionals are able to work in true partnership with us, patients will always be angry. Participants must become involved in a consultative, collaborative manner in research and not be merely passive subjects of a research process controlled by others. Chamberlin includes examples of several client-run programs. She points out that patients create jobs and salaries for professionals while patients themselves live on tiny disability pensions which are often doled out by professionals, when professionals should instead join the movement and

demand better benefits for patients. The author points out that it is particularly important that patients not settle for "rights" that are not rights at all. She gives an example of how the language in the United Nations declaration on patients rights was changed to be more restrictive. The National Institute of Mental Health (NIMH) has begun to involve ex-patients, survivors, and consumers in planning and evaluation meetings, despite criticism. Rehabilitation must not be viewed in a vacuum. Factors such as racism, sexism, classism, heterosexism, poverty, and oppression need to be factored in for professionals to see patients as not merely broken and needing to be fixed. Chamberlin states that rehabilitation must mean not only assisting with readaptation to society but recognizing the ways in which social practices prevent that readaptation. Stigma and discrimination must be honestly faced and fought.

Chamberlin, J., Rogers, E. S., and Ellison, M. L. (1996). Self-help programs: A description of their characteristics and their members. Psychiatric Rehabilitation Journal, 19, 33-42.

According to the authors, "user-run programs have proliferated in the past 10 years, yet there are few empirically-based studies about them. A survey of self-help programs was undertaken to increase understanding about the users ..., their demographics, and their perceptions of how such programs have affected the quality of their lives. Respondents were also asked about their satisfaction with user-run programs. The study was conducted using a Participatory Action Research paradigm (Whyte, 1991), using an advisory committee of persons who have used such programs, and with the intention of developing an evaluation methodology that could be replicated in future studies of user-run programs. Despite limitations in representativeness, these survey results are useful in understanding the perceptions of self-help members. Results of the survey and methodology are discussed."

The study was designed with the assistance of a consumer research advisory board, under the direction of the senior author. Three research planning meetings were held with the board to develop survey questions. The board decided to sample members of six self-help programs in various parts of the country. Because of financial limitations, only six out of 64 programs that expressed interest in the study were chosen. Programs were chosen based on geography, racial and ethnic makeup, and program type. They had to be consumer-run. Instruments for the study were also developed with help from the advisory board. Questions were developed using concepts from existing scales (e.g. quality of life and self-esteem); however, the board decided to avoid standardized psychological instruments, in favor of survey questions that were less potentially threatening to members. All ratings were based on self-report. A separate survey instrument was developed to obtain descriptive information about the programs themselves. The final instruments were pilot tested during the winter of 1991 at a local self-help program that was not scheduled to participate in the study. Data collection with the six selected programs began in March 1992 and concluded in August 1992.

Results indicated that site mission statements were developed solely by members, without collaboration with professionals or input from funding bodies. Keywords of these statements were content analyzed and found to promote empowerment and independence among members, to promote choice and self-determination, to provide peer support, and to offer education, information, advocacy, and assistance to access services. Funding included the National Institute of Mental Health, the Center for Mental Health Services, their state Department of Mental Health, their Office of Vocational Rehabilitation, county or

government boards, the U. S. Department of Housing and Urban Development, and charitable foundations. The number of full-time-equivalent staff ranged from a low of 1.5 to a high of 12.5. The most common job titles for consumers/survivors were advocates, peer support persons, resource coordinators, employment and education specialists, and residential support persons. The types of activities and services included assistance with legal problems, transportation, protection or advocacy for individual members, advocacy efforts on behalf of all persons with psychiatric disabilities, and assistance with housing. Programs were asked about the procedures that prospective members must follow to participate. Programs indicated that they had from 40 to 750 "active users" (a mean of 199 and a median of 65).

There were a greater percentage of male respondents than of female respondents. The average age of all respondents was 40.4. The sample consisted of 56.4% Caucasians, 36% African-Americans, and 7.6% other. Most respondents were single and more than half reported having children. The average age at first reported psychiatric contact was 23. Fifty percent of respondents reported currently taking psychiatric medication. The average total number of psychiatric hospitalizations was 4.8. The sample was fairly well educated, with the majority having at least a high school degree. Most respondents were not competitively employed. The median monthly income for respondents was \$575. Most respondents lived in private homes or apartments. The authors compared and contrasted demographics of the self-help sample with data from a national sample of community support clients surveyed in 1984. Respondents were questioned about the number and types of mental health services they had used in the past year. From a list of 22 possible services, respondents had used an average of 7. The most frequently used services were counseling, medications, general support, transportation, emergency services, day activities, and psychiatric hospitals. Respondents were very involved in their user-run programs, spending an average of 15.3 hours per week there. More respondents were satisfied with their housing, social situation, and physical well-being than dissatisfied. However, most members were dissatisfied or very dissatisfied with their work and their finances. Respondents reported feeling more positive about themselves as a result of self-help involvement, having more respect for themselves, feeling more productive and capable, and being more able to recognize their strengths. Significant differences ($p < 0.05$ level) were found in the impact self-help involvement had on respondents' social lives.

A 19-item questionnaire using a four-point Likert scale was administered to respondents to gather information about their satisfaction with their self-help program. Overall, programs received very positive ratings. There were no significant differences in satisfaction across the six sites. Over 90% of respondents indicated that they participated in at least one community activity and 40% indicated that they participated in five or more community activities. The author cautions about interpretation of the findings, because they represent only six of the 64 self-help programs that expressed a desire to participate, and because the researchers did not have the ability to systematically track response rates within each of the six programs.

Chesler, M. A. (1990). The "dangers" of self-help groups: Understanding and challenging professionals' views. In Powell, T. J. (ed), Working with self-help, (301-323). Silver Spring, MD: NASW Press.

This chapter looks at the dangers that professionals believe to be affiliated with self-help groups, points to vital issues in local self-help group-staff interactions

and in professional-client interaction, and discusses how professionals and members of self-help groups can more effectively collaborate.

Discussed are structural distinctions of defining self-help groups' concerns, appropriate bases of knowledge, and authority for leading the groups. Also discussed are processes and different functions of self-help groups (i.e. education/discussion, counseling/therapy, and social advocacy). This chapter discusses potential "dangers" and sorts them into two different categories: dangers to members and dangers to professionals. Perhaps the most often mentioned danger is that discussions of deeply held feelings may escalate feelings and upset people in the group. Another danger is that medical misinformation will be spread and increase unrealistic hope. Some professionals argue that self-help groups are used as a "crutch." The author notes that dynamics of all groups, including self-help groups, may be seen as dangerous. Other professionals caution against members of self-help groups becoming too involved with each other's problems. The second major reported danger, i.e. the danger to the professional, concerns the development of an anti-professional or anti-intellectual stance among group members.

This author did research about the perceived dangers of self-help groups. Chesler gathered data on 63 professionals and 35 local groups that involved families and children with cancer. Some groups worked with professionals and some did not. Fifty-seven of the professionals interviewed reported that they had heard of dangers associated with self-help groups, but only 15 professionals reported that they had evidence of such dangers. Professionals worried that parents talking about feelings might experience greater pain and distress. Professionals were also concerned that self-help groups might threaten professionals' role and status. The author discusses the monopoly on service or practice by professionals and questions why any provider should be accorded special rights, pay, and privileges. Likewise, parents who become involved with self-help begin to hold the professional accountable for his/her actions and want to comparison shop. Professionals often defend themselves by defining the behavior of clients/patients and by defining the patient-professional relationship. Finally, the chapter advocates improving collaboration between professionals and lay leaders. Chesler notes that professionals' perceptions of dangers are greater than the actual evidence of dangers found in the literature. These perceptions must be demythologized. Professionals need to educate themselves and their peers, and to share actual experiences.

Consumer/ex-patients initiatives. (1998) Community Support Network News: A Network for Caring, 5, 1-16.

This newsletter offers a range of articles about consumer/ex-patient initiatives. One author (Parrish) gives a personal account of why she enjoys her work. (This article is briefed later in this annotated bibliography.) The National Alliance of Mental Patients and the National Mental Health Consumers' Association are described. What is happening now in Washington, D. C. is briefly summarized. The technical assistance section describes different demonstration projects. Sites included are in California, Colorado, Indiana, Maine, Missouri, New Hampshire, New York, Ohio, and Wisconsin. Examples of initiatives and services by ex-patients/consumers are given. These initiatives include: The National Mental Health Consumer Self-Help Clearinghouse; Outreach, Advocacy and Training Services for the Homeless Mentally Ill; and Colorado's Consumer Case Manager Program.

Foner describes the Leadership Education and Advocacy Development Mental Health Consumer Self-advocacy Training Project of the Pennsylvania Mental Health Consumer Association, funded by Pennsylvania Protection and Advocacy, Inc. Ebert describes the Alliance Peer Advocacy Service in Syracuse, New York. Ellis writes about mental health consumers in Mississippi. Blake provides an update on the Empowerment Sponsoring Committee, Inc., which is a coalition of mental health consumers, family members, advocates, and professionals working to create Massachusetts People Organized for Wellness, Empowerment, and Rights. The Consumer Speaks Conferences in California are described. Chamberlin writes about "An International Perspective -- User Involvement in British Mental Health Services." There are a resource guide to materials related to consumer/ex-patients perspectives, initiatives, and a research brief.

Corrigan, P. W. and Garman, A. N. (1997). Considerations for research on consumer empowerment and psychosocial interventions. Psychiatric Services, 48, 347-352.

In their abstract, Corrigan and Garman write, "Consumer empowerment is a political movement that, among many goals, seeks to diminish the stigma and discrimination experienced by people with severe and persistent psychiatric disorders. This article reviews research strategies that address the methodological problems of studying consumer empowerment. Key issues include defining the subject of investigation, describing consumer-developed treatments using discovery-oriented research strategies, and sorting out the diverse roles of consumers in contemporary psychosocial programs. Consumer empowerment introduces a political paradigm into the understanding of severe mental illness, a paradigm that can be difficult to integrate with the goals of empirical research."

Corrigan and Garman describe the difficulty of defining consumers. Inclusionary definitions are more consistent with the empowerment movement than exclusionary definitions are. The authors suggest using focus groups to list positive values and beliefs to work toward a definition. The authors compare ethnic groups and consumers but caution that the comparison may be limited. Corrigan and Garman also compare consumers and persons with physical illness such as AIDS. The latter analogies seem to reflect more of the stigma against individuals with serious and persistent mental illness. The authors also discuss whether the individual or the system needs to be studied. Most research has been oriented toward the individual, an orientation that often promotes stigma. The authors recommend studying the interaction between systems and the individual. The authors review several research projects about consumer-developed programs that show the effectiveness of consumers. The findings are questionable, however, because they rest on the null hypothesis. The authors suggest directly comparing consumer-run programs to non-consumer-run programs, using discovery-oriented research. The article discusses the consumer's joint role as participant and provider and the difficulty of such a role. The authors emphasize the importance of consumer participatory action research to advance research that supports the basic beliefs of consumer empowerment.

Curtis, L. C. (1993). Consumers as colleagues: Partnership in the workforce. Center for Community Change through Housing and Support, 4-5.

Curtis synthesizes interviews with 10 persons intimately involved with the process of hiring consumers as mental health staff. The perspectives include those of consumer-run and non-consumer run agencies, employees with mental illness, and supervisors. The article discusses the definition of the "consumer"

and of possible roles. Possible roles include volunteer; on-the-job training; created positions; set-aside positions; and competitive positions. Agencies should be clear about reasons for hiring consumers and should explore their own attitudes about the capabilities of persons with mental illness. The article suggests that training programs be developed to help the consumer and non-consumer staff work cooperatively. The agency needs organizational commitment, affirmative action, clear credentials and clear job descriptions, ongoing training and support, and perspective.

Dixon, L., Krauss, N., and Lehman, A. (1994). Consumers as service providers: The promise and challenge. Community Mental Health Journal, 30, 615-625.

In their abstract the authors state, "The importance of consumers in planning, providing and evaluating mental health services has received increasing recognition. Consumer participation as staff members on professional multi-disciplinary teams describes one model of consumer involvement in providing services. This report gives the perspective of the professional leadership of such a team which employs two full-time "consumer advocates" (CAs). CAs have made significant and valuable contributions to the clinical work of the team by virtue of their street smarts, engagement skills, peer support, positive role modeling, fighting stigma, and education of co-workers. However, the CA/professional collaboration presented a number of challenging questions for ongoing discussion, including: 1) What is the role of the CAs? 2) What are the boundaries between CAs and patients and the implications of these boundaries for the potential effectiveness of CAs? 3) What supervision should the CA have and with whom? 4) What is the impact of the CAs individual experience with mental illness on their work? Examples are presented of both the clinical contribution of CAs and how the importance of addressing the above questions became evident in the work of the team. The authors found that CA's were extremely important team members; however, an ongoing dialogue between consumers and professionals is essential to operationalize this important collaboration."

Like the self-help movement for alcohol addiction anchored in Alcoholics Anonymous, the mental health self-help movement is built on the assumption that reliance on professionals is not essential to become well. Self-help groups are non-hierarchical and emphasize self-definition of needs, voluntary participation, and autonomy. There are several models within which consumers can participate in the delivery of mental health services. This report describes the experience of an experimental Assertive Community Treatment (ACT) Team, designed to provide services to homeless persons with mental illness, which employs two full-time CAs. The ACT Team was started as the clinical arm of a National Institute of Mental Health McKinney-funded research project designed to measure the effectiveness of an assertive community outreach team. Patient and family outcomes, as well as costs of the ACT intervention, are compared with outcomes of a control group who received standard services in Baltimore City. The ACT team's first patient began with the team in March 1991.

CAs played an important role in the engagement of patients. The knowledge CAs had about different characteristics of the missions, shelters, and soup kitchens, as well as other aspects of street life, was important in many ways. Street smarts were critical. The CAs could more easily than other staff put themselves in the shoes of the patient. The personal experience of the CAs with medication, mental illness, and homelessness sensitized staff and influenced how the team provided treatment. CAs became role models for the patients and spoke in language the

patients could understand. The CAs reduced stigma by challenging biases and prejudices which professional staff were not acknowledging. More casually dressed CAs seemed to suggest a tolerance that could only be expressed in actions, not explained by words. The CAs handled money for a number of patients for whom the agency was payee. This seemed to lessen the humiliation for patients. CAs took patients shopping, directly helped patients deal with the frustrations caused by their illnesses, and discussed patients' feelings and decisions regarding medication. Finally, CAs functioned as patient advocates.

In implementing this model, CAs could have perhaps used more duties and structure. Boundaries between CAs and patients and between CAs and staff were not clear enough. Supervision was a question the project wrestled with. The Medical Director provided patient-based supervision in the model. The CAs found it ironic that a credential for the job was specific experience with mental illness and homelessness. Greater turnover among the CAs than among other staff appeared in some cases to be illness-related. Several CAs had never had an equal, cooperative relationship with a provider and were uncomfortable at first. The inability to bill for the services provided by the CA was a problem.

Felton, C. J., Stastny, P., Shern, D. L., Blanch, A., Donahue, S. A., Knight, E., and Brown, C. (1995). Consumers as peer specialists on intensive case management teams: Impact on client outcomes. Psychiatric Services, 46, 1037-1044.

According to the authors, "the objective of this study was to examine whether employing mental health consumers as peer specialists in an intensive case management program can enhance outcomes for clients with serious mental illness. Methodologically speaking, this study was a quasi-experimental, longitudinal, nonequivalent control group design used to compare outcomes of clients assigned to three case management conditions: teams of case managers plus peer specialists, teams of case managers plus non-consumer assistants, and case managers only. Outcomes were measured at baseline and at three six-month intervals. Repeated-measures analysis of variance was used to assess between-group differences. The results included complete data for 104 clients. Compared with clients in the other two groups, clients served by teams with peer specialists demonstrated greater gains in several areas of quality of life and an overall reduction in the number of major life problems experienced. They also reported more frequent contact with their case managers and the largest gains of all three groups in the areas of self-image and outlook and social support. No differences in outcomes were found between clients served by teams with non-consumer assistants and those served by teams with non-consumer assistants and those served by case managers only. The authors concluded that integration of peer specialists into intensive case management programs appears to lead to enhanced quality of life for clients and more effective case management."

Clients in the peer specialist group grew more satisfied with their living situations, finances, and personal safety than clients in the other groups. In addition, the number of major life problems the peer specialist group experienced declined relative to the other groups, which suggests that observed changes in satisfaction reflected not just changes in clients' attitudes but also objective improvements in their life circumstances. Fewer clients in the peer group reported poverty as a life circumstance. In the area of client engagement in the program, the rates of contact with intensive case managers remained stable for those in the peer specialist condition while rates declined in the other two groups. Although there were no statistically significant gains in self-image and outlook and social support, peer specialist groups show the largest gains.

Fox, L. and Hilton, D. (1994). Response to "Consumers as service providers: The promise and challenge." Community Mental Health Journal, 30, 627-629.

The authors indicate that several issues are raised when consumers of mental health services are employed to provide the same services. Role definition for the consumer on the treatment team is one critical issue. The consumer on the treatment team should be an equal when it comes to supervision, pay, benefits, and status. The consumer is able to better engage others in pursuit of mental health. This capacity for engagement also requires some innovative approaches to the concept of "professional distance." The issue of relapse needs to be addressed when employing someone who has or has had a mental illness. A plan needs to be in place so other team members are not too burdened or resentful. This calls for maximum flexibility and accommodation in job description, sharing, and scheduling. Moving in and out of treatment in the community in which the team operates raises issues of confidentiality and boundaries. Using special skills and special knowledge gained from personal recovery is explored as part of a treatment approach to help others recover.

Galanter, M. (1988). Zealous self-help groups as adjuncts to psychiatric treatment: A study of Recovery, Inc. American Journal of Psychiatry, 145, 1248-1253.

Galanter states in the abstract, "In a controlled study of Recovery, Inc., a self-help program for people with psychiatric problems, the author found a decline in both symptoms and psychiatric treatment after subjects had joined the group. Scores for neurotic distress reported after joining were considerably lower than those reported for the period before joining. Scores for psychological well-being of longstanding Recovery members were no different from those of community control subjects, and fewer long-term members than recent members were being treated with psychotropic medication and psychotherapy. The author concludes that peer-led self-help groups have value as an adjunct to psychiatric treatment."

Recovery, Inc. is a voluntary, nonprofit association for mutual aid among self-described "nervous and former mental patients." There are weekly two-hour meetings which follow a particular format developed by the founder, Dr. Low. This format includes readings or an audiotape by Dr. Low, followed by patient presentations and then open exchange among members. Peer group leaders are selected after they have been members for a long time and have received training. The participants were Recovery, Inc. members and group leaders throughout each of the 211 Recovery administrative areas in North America. The research instrument was a 216-item multiple-choice questionnaire that was completed anonymously. In addition to demographics and Recovery-related activities, categories included mental health, neurotic distress, social cohesiveness, ideological commitment to Recovery, and psychiatric treatment. Respondents were 201 leaders and 155 more recent members drawn from 39 states, Puerto Rico, and Canada.

The results showed that 310 (87%) of the respondents were white, 239 (67%) were married, most were middle-aged, 256 (72%) were women, and 231 (65%) had some college education. Two hundred ten (59%) worked for pay an average of 35.1 hours per week. Only 21% were referred to Recovery via the traditional mental health system. The peer leaders' involvement in the group was greater than that of the members. Both leaders and members, however, had attended the same mean number of meetings and had themselves made the same mean number of calls to ask for mutual aid. More Recovery members reported a history of "nervous breakdown" than did the control participants; however, the Recovery

members' psychiatric status seemed to improve after joining, as reflected in their responses to items on the Neurotic Distress Scale. Forty-nine percent of leaders and 52% of more recent members had been hospitalized for psychiatric problems before joining Recovery. After joining, 8% of leaders and 7% of recent members were hospitalized. Over the course of their longer terms of membership, the leaders needed less of both professional psychotherapy and somatic treatments. Participants in this sample of Recovery members reported close ties within the group: 77% said that they "care...a lot" (4 or 5 on a 5-point scale) for the 19 participants they knew best. This closeness was also evident in their responses to items about their belief in the ideas behind Recovery. A case report is provided to illustrate the impact of Recovery membership and its relationship to psychiatric treatment.

Gartner, A. J. and Riessman, F. (1982) Self-help and mental health. Hospital and Community Psychiatry, 33, 631-635.

In their abstract, Gartner and Riessman indicate that "over the past decade self-help groups have become an important way of helping people cope with various life crises. Groups have organized to help individual members deal with a wide range of health-related and other problems. The authors define the meaning of self-help in such groups and describe the range of groups now available, including a number of mental-health-related groups. The part self-help groups play in providing social support, preventing illness and death, and reducing the need for hospitalization is discussed. The authors also examine the role of professionals in initiating and working with such groups. They point to self-help groups as one means of meeting the increasing demands placed on health and mental health service systems during the 1980s."

The authors define self-help groups and discuss their own definition. For example, they explain that self-help groups always involve face-to-face interactions and often group members enter the group feeling powerless. Numerous groups are listed and self-help groups are discussed as a form of prevention. Self-help groups have developed to replace the natural support networks that have been lost or have become disconnected as society has changed. The power of self-help groups stems from their combining a number of very important properties: the helper-therapy principle, group reinforcement, continuous intervention, an ideological perspective, and the implicit demand that members do something for themselves. The authors argue that service delivery systems in the 1980s will require a strong relationship between professionals and self-help groups. Independence from professional intervention has been part of the self-help rhetoric from the beginning of the movement. Concern has often been expressed about professionals taking control of the self-help groups. Nonetheless, professionals have been involved for a long time. However, professionals need training in how to perceive a need, establish a self-help group to fill the need, and then disengage. The mental health field is particularly affected by the possibilities of self-help as mental health services are being strained more and more to meet growing and diverse demands. Self-help becomes a way to expand human services quantitatively by reaching more people, and qualitatively by making people more independent and interdependent.

Gartner, A. and Riessman, F. (1993). Self-help and health reform. National Self-Help Clearinghouse, 1-8.

Because health care needs in the United States are rising tremendously, it is impossible for the professional care-giving system to provide all the services that are necessary. Thus, the self-help/ mutual-aid strategy becomes especially meaningful, because it turns people with problems into sources of care. A self-help approach can play a strategic role in the three key dimensions of health care reform: cost, quality, and access. Research supporting self-help has found that patients discharged from a state psychiatric hospital who were randomly assigned to participate in self-help required only-half as much re-hospitalization 10 months after discharge, compared to non-participating ex-patients. Self-help groups cost less than traditional treatment. In a survey of mental health drop-in centers, the cost of social support services provided at peer-run centers was approximately \$250 per person per year, compared to about \$500 per person per year in similar professional provider-run centers. Primary care physicians' role will be directed at providing quality care while limiting costs. There will be an emphasis on prevention and development and on use of a wide network of care, including self-help/ mutual-aid.

Although relevant groups exist, they are often inaccessible to those who need them and appropriate referrals are often not made by the professional community. On a macro-level, a national council of self-help with representation from self-help groups, consumers, clearinghouses, researchers, and health-care-providing agencies could play a coordinating role in this self-help initiative. On the local level, the task force could require that the HMO or other overseeing organization provide the community with referrals to self-help groups and with information about existing groups. Here, regional self-help clearinghouses could provide such information and access to the health-care system. Self-help groups have a vital contribution to make in a continuous evaluation of the health-care system. Self-help groups need to know about any health-care changes that are made known to professionals. Knowledge about self-help needs to be synthesized and delivered to the entire health-care community so that providers understand and appreciate the importance of self-help.

Gutierrez, L., Ortega, R. M., and Suarez, Z. E. (1990). Self-help and the Latino community. In Powell, T. J. (ed), Working with self-help. (218-236). Silver Spring, MD: NASW Press.

This chapter discusses using self-help in the Latino community to increase members' strengths and abilities. It describes several ways the self-help model can be useful in the Latino community. Cultural values of Latinos and how these values are different from those of the mainstream in this society are discussed. How the self-help perspective fits with aspects of Latino culture is also outlined. Finally, suggestions are made for professionals who have an interest in organizing self-help groups in the Latino community.

This chapter indicates that qualities of interdependence, symmetry, generosity, loyalty, cooperation, affiliation, collectivism, and social harmony are representative of the Latino self. This viewpoint illustrates how self-help could be philosophically compatible with the Latino culture. Instead of emphasizing self-help, however, the authors suggest emphasizing mutual-aid. Although Latinos are written about as a whole, many subgroups exist in the Latino community. Two of the barriers to organizing self-help groups are language and transportation. Child care and household responsibilities may limit participation of women. Many immigrants hold down two jobs and do not have the time to participate in self-help groups. Suggestions are given for organizing Latinos into mainstream, as well as "Latino only" self-help groups. The authors discuss developing Latino chapters of mainstream groups. The National Alliance for the

Mentally Ill is one example. The authors do not believe that mutual-aid groups can come about without the involvement of professionals or "linkpersons." Once Latino leaders come forward, however, the authors recommend that the "linkpersons" step away. The chapter also discusses groups that are culturally relevant to Latinos. Finally, self-help groups must be able to address a broad range of problems and must not turn away any Latinos who need support.

Howie, T. H. (1987). Oppression within the group. In Budd, S., Harp, H. T., and Zinman, S. (eds), Reaching across: Mental health clients helping each other. (188-193). Riverside, CA: California Network of Mental Health Clients.

This chapter discusses ways self-help groups can become oppressive. Conformity, standards of behavior, and judgements can all oppress members, especially new ones. Not respecting cultural differences, such as ethnic origin, national origin, social class, where a person grew up, religion, and sexual and other lifestyle preferences can also become oppressive. Harp states that differences and conflict are natural in groups. It is the taking of sides that becomes oppressive.

Avoiding debates over personality, especially debates in which the interests of the group get lost, is important. Severe oppression occurs when there is gossip about members or when members "gang up" on another member. Harp indicates that scapegoating can destroy people. Perhaps the worst form of oppression within a group is forcing a member into doing something he/she does not want to do. Another extreme form of oppression is letting philosophy or ideology become dogma for the group. Harp cautions against members becoming jealous of a highly contributing member. This chapter ends with ways to prevent oppression within the group.

Kasinsky, J. (1987). Co-optation. In Budd, S., Harp, H. T., and Zinman, S. (eds), Reaching across: Mental health clients helping each other. Riverside, CA: California Network of Mental Health Clients.

This chapter begins by defining co-optation as "the absorption into the mental health system of a heretofore viable self-help or ex-patient-run alternative" or "the intentional destruction of a self-help group by the mental health system." Kasinsky outlines the danger signals: (1) changes in the group's funding; (2) changes in the amount of decision-making power and supervision the ex-patient members of the group have over the group; (3) changes in the leadership whereby members who are not ex-patients take leadership and paid positions in the group.

Kasinsky discusses the importance of finding different kinds of funding sources and avoiding mental health system funding, especially when it involves collecting data. Another warning is given about using the language the funding source requires for grants and annual reports. Kasinsky cautions against letting that language direct and limit the self-help group's ways of thinking. Other cautions are given to ensure ex-patients are in the majority and are in leadership roles or being hired in paid positions. Many groups avoid co-optation by establishing clout in the community and through joining political action committees. Finally, Kasinsky cautions that constant criticism, self-determination, self-criticism, and evaluation are essential to guard against co-optation.

Kaufmann, C. L., Ward-Colasante, C., and Farmer, J. (1993). Development and evaluation of drop-in centers operated by mental health consumers. Hospital and Community Psychiatry, 44, (7), 675-678.

The Pennsylvania Office of Mental Health funded the development of nine consumer-operated drop-in centers, part of a statewide initiative begun in 1989 to promote consumer involvement. This article describes some of the programs and services developed by the centers and presents results of a survey of consumers' use of and satisfaction with services. During the six-month survey period, a total of 478 consumers used services and the average daily attendance at each center was 28. Most centers had one paid position supplemented by heavy use of volunteers. Most projects had collaborative relationships with a few providers who maintained a low profile in daily operations. Although consumers were highly satisfied with the drop-in centers, respondents also wanted improvements in the number of paid staff, hours of operation, management, and transportation.

The \$250,000 from state legislatures used the Involved Consumer Action Network (I CAN in Pennsylvania), which is a consumer-operated organizing agency, working closely with the Office of Mental Health (OMH). The article gives statistics on the number of inquiries and submissions regarding the project. Out of the 13 projects originally selected for funding in 1989, nine were successful in establishing centers within the first year. OMH established a process to gather information on the projects' use of funds and to evaluate consumers' satisfaction and use of services. Six core areas were examined: staffing, facilities and supplies, vocational programming, consumers' relationships with professionals, consumers' use of project services, and consumers' satisfaction with the centers. Some controversies arose in information-gathering, because the project directors wanted to avoid bureaucratic "red tape."

Each of the nine drop-in centers had a minimum of one paid staff member. All nine projects received technical assistance from providers who served as allies and consultants. Achieving balance between professional control and consumer control was a struggle. Four of the nine centers reported management problems due to competition for paid positions. The nine drop-in centers set their own hours. The space each of the centers used is described and location and access to public transportation are briefly discussed. The article provides a table giving the estimated attendance at nine consumer-run drop-in centers during a six-month period, by location of the center. Consumers' satisfaction with services was assessed during interviews and focus groups. Many consumers stated that they liked the centers' relaxed atmosphere and social activities. All consumers wanted to obtain money to expand social activities.

Finally, the article identifies characteristics of a successful center:

- Leadership and organizational skills
- Core group of consumer volunteers
- Interdependent relationships with providers
- Financial resources and accountability
- Planned social activities
- Ongoing recruitment of new members

Kennedy, M., Humphreys, K., and Borkman, T. (1994). The naturalistic paradigm as an approach to research with mutual-help groups. In Powell, T. J. (ed), Understanding the self-help organization: Frameworks and findings. (172-189). Thousand Oaks, CA: SAGE Publications.

Kennedy, Humphreys, and Borkman present an alternative way of studying mutual-help groups, with what they call the "naturalistic paradigm." The most popular belief structures now used for this research, which are the "positivist and post-positivist paradigms," are described and criticized. According to the authors, these two paradigms "hold that reality exists out there and is subject to fixed natural laws and mechanisms." A summary of the criticism of positivist and post-positivist paradigms is given. Because people have seen so many problems with these beliefs, alternative paradigms for studying mutual-help groups have developed.

The naturalistic paradigm is based on believing that "objectivity" (or "absolute truth") is impossible. The social "reality" is being created by a person, who is usually in interaction with other people. According to Kennedy, et al., "The naturalistic paradigm assumes that all aspects of the phenomenon under study are interdependent and mutually interacting so that the determination of linear causality is impossible and inappropriate." The standards for judging naturalistic research include credibility, transferability, dependability, confirmability, fairness, and authenticity. The advantages of doing research about self-help groups with the naturalistic paradigm are described, along with examples of how the research can be used. Calls for naturalistic and qualitative research (which uses descriptions and people's own accounts of their lives, rather than using numbers) have gone out, but little of this research has been conducted.

Naturalistic research tries to work with self-help group members to determine how members benefit from the groups. The naturalistic approach asks for the researchers to be open about their subjectivity, meaning their own histories, prejudices, individual beliefs, hopes, and interests, etc. The authors stress how important it is to explore the range of experiences by group members. Kennedy, et al. caution that the information gained from a study like this must be understood in a context.

Outcomes like changes in world-view are usually not noted with traditional research. Members of self-help groups do not usually want to expose very personal changes to researchers who seem cold and distant. In contrast, the naturalistic approach to the study of self-help groups allows members to collaborate and to see the process of research as mutual, combining the different views and experiences of equals. The chapter concludes that the naturalistic approach will not solve all the problems related to studying self-help groups. The authors summarize some of the tough questions that need to be asked of the naturalistic approach and encourage researchers to consider both the approach and the questions.

Kessler, R. C., Mickelson, K. D., and Zhao, S. (1997). Patterns and correlates of self-help group membership in the United States. Social Policy, 27, 27-46.

In their abstract the authors state, "Data from a recently completed national survey are presented on patterns and correlates of self-help group participation in the United States. Over twenty-five million Americans are estimated to have participated in a self-help group at some time in their lives; over ten million, in the past 12 months. These estimates are conservative and might, in fact, be substantially lower than the actual numbers of participants due to the fact that groups organized or facilitated by professionals were excluded. Clearinghouse data show that professional facilitation is common in contemporary self-help groups."

Synthetic cohort analysis suggests that group membership has been rising over the past three decades, except in groups concerned with eating problems or with life transitions. Although self-help groups exist to address a wide range of life problems, more than one-third of participants -- accounting for more than 70% of self-help meeting attendance -- are involved in groups for substance use problems. Large portions of people who use self-help groups for substance (50%) and emotional (76%) problems also see a professional for the same problems.

Self-help group participants are more likely than non-participants with the same problems to be young, female, white, and unmarried. Participants generally have lower incomes than non-participants, although the opposite is true in groups for eating disorders. People reporting less support and more conflict in their social networks are more likely to participate in self-help groups than people with more supportive networks. Generally, people with a lower sense of personal control and higher levels of neuroticism are more likely to participate in self-help groups. Extroversion, openness to experience, and commitment to personal growth are not significant predictors of self-help participation.

In the introduction, the authors indicate that the effects of self-help groups are part of a long-standing neglect of the self-help movement among human services professionals. The largest single sector in the American mental and addictive disorders treatment system is the self-help sector, according to a recent national survey. In this study 3,032 respondents were recruited and the ages were restricted to between 25 and 74. Participants were interviewed for 30 minutes over the telephone and also given a self-administered mail questionnaire. The mail questionnaire provided the following definition of self-help groups: groups organized and run by people who get together on the basis of a common experience or goal to help or support one another." More than one in six respondents participated in a self-help group at some time and 6.9% did so in the past year. Forty percent of the respondents who reported ever participating in a substance abuse group were still doing so during the past 12 months. Low median attendance in the past 12 months, in the range of between one and four meetings, is found among members of life transition groups, bereavement groups, disability groups, parent support groups, and groups for the families of people with physical illnesses.

The article discusses differences in lifetime participation. For example, the data suggest a steady increase in lifetime participation in self-help groups across the cohorts included in this survey. There was a substantial increase in lifetime participation in substance use groups after World War II and a steady increase also in more recent years. Many people who use self-help seek professional treatment also, particularly those who have psychiatric disabilities. Women are more than twice as likely as men to participate in self-help groups, with the exception of people with substance use issues. African-Americans overall are only half as likely as Caucasians to participate in self-help groups, but this difference is largely due to an extremely low rate of African-American participation in groups for people with eating problems. The study estimates that 25 million Americans have participated in self-help groups at some point, and this is considered a conservative estimate, since the survey excluded people under 25 and over 75 and did not include groups led by professionals. The study estimates that 10 million Americans participated in a self-help group in the past year.

Kopolow, L. E. (1981). Client participation in mental health service delivery. Community Mental Health Journal, 17, 46-53.

According to Kopolow, client participation is an inexpensive way of providing increased support and continuity of care, but it is underused. Self-help programs are not being used in the day-to-day operation of the community mental health centers (CMHC). Use of self-help programs in CMHC operations can surmount the difficulties of "limited motivation, capacities, organizational framework, and resistance by clients and professionals."

Kopolow discusses the ex-patient movement and the nearly unanimous opposition to forced treatment and the belief in patient input and direction of care. Kopolow describes seven potential benefits of more actively involving patients in their treatment. In 1981, data showing patient or ex-patient involvement in CMHCs were not even collected. In independent self-help programs, ex-patients provide support, friendship, and tolerance instead of psychotherapy, medication, and structure. The traditional mode of treatment often results in dependency and self-doubt. Kopolow states, "To offset this liability resulting from dependency, ex-patient groups have sprung up in all regions in the country."

Cooperation between ex-patient self-help groups and CMHCs can be beneficial. An example of this cooperation is given. In addition to independent self-help programs and collaborative programs, there is a third type of self-help program, advocacy. According to the author, this group has potentially the greatest impact on the mental health system. Kopolow explains that advocates must have their client's best interest at heart and must be loyal to the mission of helping clients obtain their rights and entitlements. CMHC staff may be reluctant to involve patients because of fear of losing staff power and ex-patients may be reluctant to collaborate because of fear of losing their independence and being co-opted. Nonetheless, Kopolow argues for greater collaboration.

Lieberman, M. A. and Snowden, L. R. (1994). Problems in assessing prevalence and membership characteristics of self-help group participants. In Powell, T. J. (ed), Understanding the self-help organization: Frameworks and findings, (32-49). Thousand Oaks, CA: SAGE Publications.

Lieberman and Snowden use secondary analysis (which studies information already collected by other people) to find how often and how widely self-help groups are attended. Two of the surveys covered large household probability samples, and a third survey looked at self-help groups in California. Accurately assessing self-help group participation based on the surveys is the focus of this chapter.

In the first study, 18,000 participants, who were not living in institutional settings, were analyzed. The survey asked a series of questions about resources used for psychiatric disorders and used for help with drugs and alcohol. The lifetime use of self-help groups was 3.6% for men and 2.2% for women. Other demographic statistics are also given. Caucasian groups show highest use, closely followed by Hispanics, and the African-American population reports the lowest use. Self-help group participation and psychopathology were analyzed. Over their lifetime, self-help group participants were five times more likely than nonparticipants to be classified as mentally ill using the DSM-III criteria. These differences disappear when current use and current DSM-III diagnosis are examined. Statistics are given on the relationships between types of mental illnesses and use of mental health services and self-help groups.

Another survey focuses on households, psychiatric treatment and symptoms, and use of self-help groups. During 1980, 5.6% of adults consulted mental health professionals, 2.9% participated in self-help groups, and 2.2% participated in some type of experiential education (or growth groups). The relationship between stress and the types of sources of help is analyzed.

The final study reviews self-help groups in California. Statistics are given on problems addressed by groups and whether the groups are led by a professional. The estimated number of participants is discussed, as are selected characteristics of self-help groups. Those characteristics include leadership, new members, and services.

Luke, D. A., Roberts, L, and Rappaport, J. (1994). Individual, group context, and individual-group fit predictors of self-help group attendance. In Powell, T. J.(ed), Understanding the self-help organization: Frameworks and findings. (88-114). Thousand Oaks, CA: SAGE Publications.

According to the authors of this chapter, self-help is moving from simply an alternative treatment to a social movement. This chapter presents data on how participation of the member can be influenced by the "fit" between the member and the particular self-help group. Attendance and participation are connected and statistics that back up the connection are given.. The authors discuss different ways of defining the fit, such as self-help group/specific person, characteristics of the first meeting attended by the individual, and individual/other group members fit.

This study was part of a full scale assessment of GROW, Inc., a self-help group for people with serious mental illness or psychiatric hospitalizations. Within a 27 months, trained observers/participants collected data as they attended 527 meetings of 15 different GROW groups in central Illinois. Eight hundred, sixty-one different people, attending at least one GROW meeting, were observed. Participants ranged in age from 15 to 85 and tended to be single, Caucasian, and female and to have some education beyond high school.

An identification number was given to each participant to record attendance. Monthly attendance data were used to determine attendance duration for each member. A brief questionnaire about items such as education, marital status, work status, previous hospitalizations, and level of functioning was filled out by each member. The statistical method was discussed.

For the three models presented, the findings about participants most likely to drop out were:

1. For the individual characteristics model: younger, less educated, currently or previously married, and high functioning.
2. For the group context model: members who attend meetings that are more than 2:1 female.
3. For the individual-group dissimilarity model: different hospitalization history, different marital status.

The authors of the chapter emphasize that the concept of individual-group fit is critical to understanding how people enter a self-help setting and become participating members. This research is only the beginning and only exploratory. The chapter ended with four suggestions:

1. First meetings are important;
2. Be clear about for whom your group is organized;
3. Find out more about why people are or are not joining;
4. Recognize the need for change.

Lyons, J. S., Cook, J. A., Ruth, A. R., Karver, M., and Slagg, N. B. (1996). Service delivery using consumer staff in a mobile crisis assessment program. Community Mental Health Journal, 32, 33-40.

In their abstract, the authors state, "Interest has developed in the use of mental health consumers as staff members in community programs for persons with serious mental illness. The present study investigates consumer service delivery in a mobile assessment program designed to assist homeless people with severe psychiatric disorders. Consumer and non-consumer staff were generally comparable. Results suggest that consumer staff engaged in more street outreach and were less often dispatched for emergencies. There was a trend for consumer staff to be more likely to certify their clients for psychiatric hospitalization. In sum, consumer staff appear to provide a valuable contribution to this form of service delivery."

The introduction discusses the consumer movement, consumer staff, and mobile crisis assessment. A more detailed description of the methods of the study is given. The mobile crisis unit was funded in 1989 to serve a large Midwestern city. Nine consumer staff members were hired. Two consumers and two non-consumers qualified as examiners, who were able to hospitalize clients. For the first two years of the study, service data were collected on each open case. The results suggest that consumer staff can be a valuable addition to a mobile assessment program. There were few differences in the descriptions of clients served by consumer and non-consumer staff. There were several differences between the two groups in how they delivered services. Consumer staff engaged in more mobile outreach. Consumer staff teams were less likely to be dispatched in an emergency and tended to involuntarily hospitalize by certificate more often.

Madara, E. J. (1997). The mutual-aid self-help online revolution. Social Policy, 27, 20-26.

Online groups are growing because they are meeting otherwise unmet needs. Madara gives several eye-catching examples of how online services have been used. Online self-help networks go out of their way to get information to people. Online, any user can be of help to any other user. People who are immobilized by physical disabilities can participate. Madara gives examples of finding and developing communities online and discusses several advantages of online services, including no signs of social status, age, dress, weight, race, etc.

People dealing with rare disorders are especially helped by the internet. Madara points out how self-help groups are able to pool their members' experiences, knowledge, and practical information. Madara also discusses the down side of online networks, with the primary disadvantage being lack of universal access. Other drawbacks include inappropriate verbal behavior or harassment, junk email, intentional deception, and unethical research. Madara concludes that despite barriers and problems, online support groups and networks are growing and will no doubt continue to be use.

Madara, E. J. (1990). Maximizing the potential for community self-help through clearinghouse approaches. Prevention in Human Services, 7, 109-138.

Madara provides an overview of self-help groups and their relationships to prevention and mental health, suggesting that mental health centers would benefit from increased use and support of groups. He also suggests that the self-help clearinghouse approaches may be of special benefit. The development of an integrated and multi-disciplinary self-help clearinghouse approach is described. This approach will increase the awareness, use, and development of mutual-aid/ self-help groups in the community. The article contains examples of strategies and accomplishments in this area. Principles and concepts important to professionals working with groups are discussed. Likewise, trends in the development of health-related groups and in computer conferencing are discussed.

In his overview, Madara cites the President's Commission on Mental Health (1978), which recommended increased linkage between mental health services and community support networks. Madara especially promotes self-help clearinghouses that help people find and form self-help groups. He suggests reasons increased mental health agency involvement with self-help groups can be useful: prevention, social networking, reducing incidence, etc.

Madara discusses professional involvement with self-help and the roles professionals have played in supporting groups. A major problem many professionals face is that they are not educated about self-help groups. The New Jersey Self-Help Clearinghouse was developed to educate professionals. Madara goes on to describe the development of self-help clearinghouses. He discusses goals, such as increasing the use of self-help groups by referring clients and clients' families to self-help groups and providing in-kind support to self-help groups by helping to arrange for flyers, telephone services, meeting space, secretarial services, mailings, and so forth.

The New Jersey Self-Help Clearinghouse and its history are described. The Center's first contact with self-help groups was an effort to simply identify their number and availability. Madara discusses how the Consultation and Education Department became known regionally for maintaining an extensive resource listing. Group development strategies emerged and a layout of that process is given. Clearinghouse operations and rationale are discussed. Outreach and education service are described, as are consultation and training service, the main thrust of the Clearinghouse program.

A section on empowerment versus enfeeblement is provided, with examples of how professionals can strengthen or weaken groups. Often the weakening of a group is done accidentally. Over the past few years, many professionals, institutions, and government agencies have become interested in self-help. Professionals have a responsibility to respect and support those empowerment efforts for the ultimate benefit of their patients and communities. Madara gives some perspectives on additional self-help trends. People with various individual illnesses and their families created health foundations, societies, and agencies dealing with their illnesses. As new health problems, such as AIDS and Alzheimer's, develop, it is often self-help groups that are the first to offer assistance. Madara concludes that self-help groups need to increase in number and size. One important way agencies and clearinghouses can tap the rich resource-building potential of self-help is to link people needing support with the self-help groups. Finally, group autonomy and ownership should be respected.

Madara, E. and White, B. J. (1997). On-line mutual support: The experience of a self-help clearinghouse. Information and Referral: The Journal of the Alliance of Information and Referral Systems, 19, 91-107.

This article discusses several forms of online mutual support/self-help, including benefits like overcoming barriers of time, distance, and disability -- and also describing some disadvantages. The authors conclude that this new tool has the power to help people become empowered and create their own communities in which they can share information which will help them overcome or cope with their obstacles.

The article discusses the beginning and growth of online self-help, and mutual support using commercial computer information services. The authors review CompuServe, America-On-Line, and Prodigy, pointing out that traditional self-help groups have been late to arrive online. Several dozen self-help groups are available to individuals, and now online services provide thousands of possibilities for those same individuals.

The authors also discuss bulletin board systems (BBSs). Hundreds are available across the country. A description of BBSs is given, along with how to use them. The article provides internet addresses to find a comprehensive searchable listing of BBSs and a comprehensive listing of freenets.

Mutual support through the internet is discussed. Self-help support networks usually take three primary forms:

- 1) Mailing lists or list serves
- 2) Usenet network, which provides access to thousands of News groups
- 3) World Wide Web

In addition, many people develop personal web sites where they share information and experiences. On the American Self-Help Clearinghouse, over 300,000 individuals per year are served and the internet is also working to assist in the development of new support networks.

The authors discuss characteristics of online support networks. Online services are available 24 hours per day, are less structured than traditional self-help groups, are an equalizer, are mostly anonymous, and can be used by many more people than self-help groups can.

Online networks provide social support, practical information, shared experiences, positive role models, helper therapy, empowerment, professional support, and advocacy. Online services are overcoming barriers of distance, time, and disability. Barriers to universal access, however, remain. Lack of universal access to telecommunications systems, resources, and networks represents a significant barrier. The authors advocate for universal access.

Maton, K. I. (1994). Moving beyond the individual level of analysis in mutual-help group research: An ecological paradigm. In Powell, T. J. (ed), Understanding the self-help organization, (136-153). Thousand Oaks, CA: SAGE Publications.

Maton makes a persuasive case for using the "ecological paradigm" for mutual-help research. A table, which represents a selected listing of variables important to self-help groups, is provided. Variables, such as focal problem, climate, structure, and well-being, are listed, and the levels of analysis include individual, group, and community. The types of vital self-help research hypotheses generated from an ecological paradigm are discussed. Variable domains and pathways through which well-being could be influenced via group characteristics are discussed. For example, groups with better developed ideology, climate, structure, and helping mechanisms are expected to have greater influence on the individual's adoption of similar characteristics. Maton indicates that more empirical research is needed to find out which variations in group-helping ecology are linked to member well-being and how these patterns differ across dimensions of the group problem. Likewise, more research into member-group fit and member well-being is needed.

The influences of group, member, and community characteristics on group effectiveness and stability are discussed. Group, community, or member characteristics expected to be influenced are described. Maton predicts that the three areas of impact are lay and professional ideologies, referral networks, and community epidemiology.

Finding data that span many different categories and many levels of analysis is very important. Maton describes sampling and measures. He also emphasizes the importance of cross-domain (or cross-category)/within-level interactions, as well as cross-level interactions with the possible moderating effect of descriptive analysis. Finally, the prospect of combining ethnographic and quantitative research is discussed.

Menz, F. E. (1994). Constituents make the difference: Improving the value of rehabilitation research. Unpublished manuscript.

Menz states, "This paper discusses the participatory research model used by the Rehabilitation Research and Training Center at the University of Wisconsin-Stout. The goal of the presentation is to elaborate on the value added to the research process and relevance of research applications when research is rehabilitation need based and the research-to-applications process model is used. The sections of the paper cover the following: (a) What makes the Center work setting unusual for participatory approaches; (b) how the participatory model came about at the Center; (c) the two components of the model; (d) constituents and constituent involvement; (e) three examples from Center's use of the model; (f) guidance for making participatory models work; and (g) finally, a discussion of some of the promises and potential pitfalls of participatory models from the author's experience."

Studies are all planned around six stages of participatory research methodology: (1) identifying and prioritizing issues; (2) designing research plans; (3) collecting research data; (4) analysis and reporting; (5) synthesis and dissemination; and (6) transfer and application. Modifications of the research plan and the shaping of the potential products all come from the input and interactions between staff and the Constituency Advisory Committee members. The methodology helps to increase the likelihood that each study will yield additive value and will be completed in a timely manner. The research methodology is iterative and regenerative. This participatory methodology provides external reality checks so that there is higher potential for solving important problems in rehabilitation. The approach requires scientific rigor. The Center's program is a five-year network of

closely related approaches for achieving solutions that may be used in different kinds of communities and by practitioners and consumers from different walks of life and different cultures, who have different disabilities. The more new knowledge is in contrast to commonly accepted practices, the less likely the knowledge is to be adopted through passive methodologies in the research-to-application process. This methodology recognizes that substantial change occurs over time and requires a variety of methodologies. The audiences of the program are clearly defined community-based staff and consumers. All published materials from the Center are made available in alternate formats appropriate to the needs of persons with disabilities and their families.

The article includes the following tables:

- (1) a classification of research constituencies;
- (2) examples of constituents' complementing each other in the research process;
- (3) functions for constituents throughout the research process;
- (4) a planning guide for involving constituents throughout research;
- (5) a schema for evaluating constituency involvement.

The examples of research projects are community-based rehabilitation needs of Native American people with disabilities who live on a reservation; development of the vocational assessment protocol for planning and case management for persons with traumatic brain injuries; and development of a state rehabilitation plan for Ohio. In each section, constituencies, constituency functions, researcher functions, and special features that make the research work were identified. The author discusses assumptions about and definitions for research. He lists unresolved issues including research procedure issues, administrative and institutional issues, and ethical and evaluative issues.

Mowbray, C. T., Chamberlain, P., Jennings, M., and Reed, C. (1988). Consumer-run mental health services: Results from five demonstration projects. Community Mental Health Journal, 24, 151-156.

According to the authors, Project Ease-Out was initiated in a rural area to provide support to persons making a transition from the hospital to community living. A satisfaction survey showed success in the areas of interactions, responsiveness, communication, and outcome. A major problem encountered was turnover among advocates. The Companions Program, also in a rural area, matched clients with volunteers to provide relationships in which clients could develop and practice social skills and engage in social activities. Although the goal of maintaining 12 matches was never achieved, progress was made in increasing eight matches in the first 12 months to 10 in the next six. There were few terminations and most matches continued beyond the required six months. The major problem was finding men to match with male clients. The goals of Project Stay were to provide a support network and help with life maintenance independence in the community. Contacts provided were 9,560 in response to 562 requests for assistance. Major categories were housing, transportation, legal, welfare, mental health, and other. Demographic and functioning level data on Project Stay clients were similar to data on inpatients. Daybreak Drop-In Center was developed in a suburban county to provide opportunities for

consumers to enjoy activities and mutual support in an unstructured setting. A participant satisfaction assessment indicated favorable responses in a 10 to 3 ratio. Transportation was a difficulty at first, until the CMHC provided a van. Members were at first reluctant to locate their meeting place at the CMHC because of the possibility of stigma. Another problem at first was "non-mental health" attendees. The objectives of Winners Janitorial Services, a suburban project, were to establish a profit-making, consumer-owned and -operated, for-profit janitorial service, and to provide training and janitorial work for stockholding consumers. Winners employed a total of 11 consumers. Employment averaged 25 hours/week, at the federal minimum wage. The project received good local support but could not find enough customers to make a profit, so it joined with a sheltered workshop, enabling consumers to continue their employment/training experience. The major problems with Winners were the supervisor's inability to market the service and the project developers' lack of business experience. Winners was never consumer-run. Since many of the consumers were on SSI, the amount of money they could earn without losing benefits was very small, thus interfering with full employment goals. The authors saw the consumer-run projects as successful, indicating the productivity and diversity of services possible among consumer groups. Costs of services were strikingly low due to minimum wage salaries paid to consumers and extensive use of volunteers. The projects filled important needs of the consumers and showed good cooperation with the community.

Mowbray, C. T. and Moxley, D. P. (1997). A framework for organizing consumer roles as providers of psychiatric rehabilitation. In Mowbray, C. T., Moxley, D., Jasper, C. A., and Howell, L. L. (eds), Consumers as providers in psychiatric rehabilitation, 35-44. Columbia, MD: International Association of Psychosocial Rehabilitation Services.

The authors present a framework and topology for describing and understanding the diverse ways in which consumers are involved in service provision in psychiatric rehabilitation. The purpose of this chapter is to acknowledge the diversity involved in consumer role innovation; to better understand the barriers and problems associated with consumer service provision, with experiences and outcomes that can be systematically analyzed; and to better understand and formulate solutions and policy responses using more systematic analysis. The authors discuss a framework for organizing consumer alternatives in the provision of services or supports in psychiatric rehabilitation. The two major components of this framework are the control of the consumer-based alternative and the purpose of the consumer-based alternative. This two-dimensional framework produces four types of consumer role innovations: consumer-run alternatives, consumers as employees, self-help alternatives, and consumer initiatives.

Mowbray, C. T., Moxley, D. P., Thrasher, S., Bybee, D., McCrohan, N., Harris, S., and Clover, G. (1996). Consumers as community support providers: Issues created by role innovation. Community Mental Health Journal, 32, 47-66.

Using data from Community Support Program-funded research demonstration projects designed to expand vocational services offered by case management teams serving people with serious mental illness, this article examines the issues created by employing consumers as peer support specialists. Roles and benefits of these positions are analyzed. Challenges experienced by specialists, the structure of the specialist position, the mental health system and the community, and personal issues are analyzed using data from the focus groups and the

project's management information system. Role definitions, supports for role effectiveness, and the structuring of these types of positions are discussed.

The peer support specialists (PSSs) provided services to assigned individuals. Specialists might help consumers prepare resumes, set up bank accounts, acquire clothing for interviews or work, or learn the bus system. Roles and benefits of these positions were analyzed by collecting service activity logs (management information system data) and focus group data. Of the 263 persons served, 117 or 44% received some direct service from a PSS. Five to six PSSs worked per month, seven hours per week. The PSS staff worked with about 30 clients per month. The focus group sessions provided a discussion of the PSS role as well as an identification of challenges presented to PSSs personally, by their role, by the CMH system, and by the structure of the PSS position itself. The article provides suggestions for supports and structures to increase role effectiveness of the PSSs. The mission and culture of community support systems need to be broadening opportunities for stakeholders other than professionals, particularly for consumers. Consistent mentoring and supervision of consumer employees is needed. Opportunities for education and advancement need to be available. The article concludes that consumers as community support workers can make a unique contribution to their peers within the community and on the job site. The authors point out that this role innovation can create considerable ambiguity, role conflict, role strain, and personal stress for the incumbents of these positions. However, the development and broadening of employment opportunities within community support systems is vital.

Mowbray, C. T. and Tan, C. (1992). Evaluation of an innovative consumer-run service model: The drop-in center. Innovations and Research, 1, 19-23.

In their abstract, Mowbray and Tan state, "This report describes the development and operation of demonstration projects designed to implement an innovative service model: the consumer-run drop-in center. Results are presented from a process evaluation, focusing on the extent to which the centers meet programmatic expectations, collecting retrospective satisfaction and impact assessments from participants, and examining differences in operations across the six centers studied. The evaluation found that the centers were meeting their mandates to provide acceptance, social support, and problem-solving assistance. The intended target population of persons with serious mental illness was being served. High levels of satisfaction were found, and participants reported feeling that they actually ran their centers. Retrospective accounts of positive effects of drop-in center participation were obtained. Consumer ratings varied across the centers, but satisfaction did not relate to attributes of a center's physical environment."

Some problems with relationships with the mental health treatment system in some locations, with funding levels, and with full participation of some subgroups of consumers were identified. Certain issues need attention in order to replicate this model, and to continue operations of the existing drop-in centers.

The article provides an introduction and background to the self-help movement, in addition to discussing the methodology of the study. The major data collection was through interviews with drop-in center participants via two site visits at six drop-in centers in Michigan. One hundred and twenty mental health consumers from the centers were interviewed. Questions in the study were: "What do consumer-run drop-in centers do?" "Are the centers really consumer-run?"; "What are the differences among the six centers?"; "Are drop-in centers helping

their members?"; "What relates to member satisfaction with centers?"; and "Do all participants benefit equally from their centers?" The authors conclude that these centers were favorably evaluated by most consumers. This suggests that centers are worthy of funding and development by consumers working with advocates. These centers are truly consumer-run. Consumers not only need other consumers to start up and run this innovative model; they also need assistance (when it is asked for) from the professional mental health community. Funding needs to increase. Most participants, especially regular attendees, benefit. However, those consumers reluctant to speak out must be reached. The final recommendation of the article is that the centers be evaluated as a regular part of operations. Accountability and monitoring should play key roles in ensuring that goals of funding agencies, advocates, and recipients themselves are being met..

Neighbors, H., Elliot, K. A., and Gant, L. M. (1990). Self-help and Black Americans: A strategy for Empowerment. In Powell, T. J. (ed), Working with self-help. (189-217). Silver Spring, MD: NASW Press.

Neighbors explores several strategies for black people's progress, including the strategy of self-help. Since a racist society causes most of the problems facing blacks today, most black self-help organizations use efforts geared toward social and economic change. Traditional self-help for blacks has focused on improving personal competence to become more successful in the present system. There are many combinations of self- and system responsibility offered to explain and improve the status of black Americans. The chapter assumes that the "system blame" viewpoint leads to less self-determination than the civil rights and Black Power viewpoints do, and that too much blaming the system hurts traditional black self-help. The authors conclude that self-help can foster a more adaptive view of the black economic condition. People who help themselves and others are attempting to take control.

The chapter discusses both history and current efforts in self-help organizing. These efforts include self-help for economic, political, and social development; neighborhood-based groups for community development; church-based organizations for community development; black social institutions; self-help groups for coping with physical illness and death; groups to strengthen black families and youths; self-help organizations founded by black women; self-help organizations for black professionals; black chapters of mainstream self-help organizations; and self-help for black special-interest groups. This chapter approaches self-help from a social and structuralist viewpoint, i.e. the argument that points to the social cause of racism, discrimination, and injustice. On the other hand, the "self-blame/system blame" dichotomy runs through all discussions of self-help in the black community. Personal responsibility for advancing oneself as well as the group is important. A case against self-help is discussed briefly. The chapter concludes with a discussion of one of the most effective functions of black self-help, that of empowerment. Many black Americans are wondering where the 60s and 70s ideas of self-determination and self-sufficiency have gone. Governmental interventions like welfare and affirmative action may have dampened individual-level responsibility for solving black problems. Recommendations include development of theory for self-help programs within the black community; systematic, thorough, and longitudinal research geared toward etiology, maintenance, and success of self-help groups; and the extension of principles of self-help to all segments of black communities.

Noordsy, D. L., Schwab, B., Fox, L., and Drake, R. E. (1996). The role of self-help programs in the rehabilitation of persons with severe mental illness and substance use disorders. Community Mental Health Journal, 32, 71-81.

Substance abuse treatment programs in the United States frequently incorporate self-help approaches, but little is known about whether individuals with dual disorders use self-help groups. This article reviews several current studies on the role of self-help programs in treating substance use disorders among individuals with severe mental illness. These studies indicate that only a minority of individuals with dual disorders become closely linked to self-help. Psychiatric diagnosis and possibly social skills are linked to participation. Dually disordered consumers often experience 12-step philosophy and jargon as distancing and insulting. The authors suggest incorporating self-help approaches into the comprehensive community care of individuals with dual diagnosis.

Eighteen patients with alcoholism and schizophrenia were treated continuously between 1987 and 1991 in a community mental health center-based dual-disorder program that included intensive case management, substance abuse treatment groups, and linkage to self-help groups in the community. Linkage to self-help was promoted through development of motivation to attend meetings, education about the content and format of meetings, transportation, and a "double trouble" AA meeting specifically for people with dual disorders. The 11 people who attained full remission from alcohol disorders were compared with the 7 people who did not. Several clients in this study found self-help programs useful and were committed to participation. However, many people reacted negatively to the use of 12-step philosophy and jargon by clinicians.

Two other studies are reviewed. One is a survey of self-help use among a group of individuals with dual disorders who were treated by case management teams in the community, and the other is a follow-up of attendees of a residential dual-diagnosis program to evaluate outcomes, including self-help use. Both studies show that few individuals use self-help groups consistently over time, despite the programs' success in getting the majority of individuals to attend self-help meetings at some point. Diagnosis appears to be associated with intensity of self-help use in these study groups. Regular attendance at self-help programs seems to be more common among individuals with affective disorders than among those with schizophrenic disorders. Finally, better social ability appeared to be associated with use of self-help programs.

Parrish, J. (1988). The consumer movement: A personal perspective. Community Support Network News, 3, 1-3.

Parrish gives a personal account of what motivates her to do the work she does with the National Institute of Mental Health (NIMH). She explains that she is drawn to the individuals who have experienced the hardships of a severe mental disorder. The projects she has been involved in have been fulfilling because they affect so many people. She is also drawn to the concept of consumer empowerment.

Penney, D. (1997). Friend or foe: The impact of managed care on self-help. Social Policy, 48-53.

Penney advocates marketing self-help to managed care and explains managed care organizations (MCOs). Clear paragraphs define and describe, briefly, what MCOs are. Penney presents MCOs as first and foremost looking out for their

financial well-being. Thus, self-help must be promoted as an economically good thing for MCOs. Penney talks about learning to speak the language; about bringing research to light that finds, for example, a relationship between self-help and improved survival rates or fewer mood disturbances for women with breast cancer.

Penney discusses health-care changes that may be beneficial to self-help groups. She lists a number of trends as they were discussed in Riessman and Carroll's Redefining Self-Help: Policy and Practice. Penney goes on to discuss two possible scenarios for the implementation of managed care for people receiving Medicaid. One is a best case scenario and the other is a worst case scenario. Supporters of self-help must take care that self-help is not used by MCOs to avoid their legal responsibilities to provide adequate health care. Other issues around the funding of self-help users and self-help providers need to be resolved. Much controversy exists in this area.

Policy in perspective. (May 1991). Mental Health Policy Resource Center. 1-8.

This edition is dedicated to self-help and includes research on self-help, examples of self-help, consumer/professional perspectives, and self-help resources. The edition begins with an article entitled "The Growing Mental Health Self-Help Movement." It discusses the numbers touched by self-help groups, what groups do, how they work, how they relate to "the System," the future of self-help, and policy implications. The article was adapted from materials on mental health self-help prepared for MHPRC by Susan Baird Kanaan. National Institute of Mental Health - funded studies of self-help are briefly summarized. The Center for Self-Help Research and Knowledge Dissemination, the Center for Psychiatric Rehabilitation, and the Center for Self-Help Research are all discussed. Examples of self-help groups and support centers include the Anxiety Disorders Association, National Association of Psychiatric Survivors, National Depressive/Manic Depressive Association, National Mental Health Consumers Association, On Our Own, Inc. of Baltimore, National Alliance for the Mentally Ill, Parents Involved Network, Oakland Independence Support Center, and St. Louis Self Help Center. An interview with Judi Chamberlin and Richard Lippincott explores consumer/professional perspectives, including questions like "What should policymakers be thinking about regarding self-help groups?" and "Are there ways in which professional/consumer collaboration can respond to these concerns?" A self-help core bibliography is provided. Jennifer Hartog reports on the Mental Health Liaison Group meeting. Other tidbits are the National Association of State Mental Health Program Directors recognizing the potential, unique contribution of mental health consumers; a brief discussion of diversity in Baltimore; online highlights; self-help: a Canadian perspective; and a brief discussion of GROW.

Rogers, S. (1996). National Clearinghouse serves mental health consumer movement. Journal of Psychosocial Nursing, 34, 22-25.

With the advent of managed care, the consumer/psychiatric survivor movement is in an ideal position to benefit from radical changes forthcoming in services to people with psychiatric disabilities. However, to maximize gains from the reorganization, the movement will have to organize itself. The National Clearinghouse organized Alternatives '96 - "Creating Healing Alternatives for Real Health Care Reform" --to explore and develop strategies for this process. The article describes the mission of the Clearinghouse and the survivor movement. The Community Support Programs (CSPs) are based on creating

opportunities rather than fostering a lifetime of dependency and disability. CSPs try to tailor programs to people, rather than people to programs. The article discusses relevant computerized techniques, such as databases and the Internet. The Clearinghouse recently hosted the Second Annual National Mental Health Consumer/Survivor Public Policy Forum and invited consumer/survivor advocates to share effective strategies that they have used to gain access to the health care reform planning process. These forums try to get consumers involved, so that consumers and managed care executives can sit across the table from each other and engage in real dialogue about the issues that matter to them. Managed care is complex and for consumers to have an impact, they need to understand it. Likewise, executives need to understand consumer needs. The best chance for consumer-run services to play a larger role in these public mental health systems controlled by managed care will be to make new alliances that secure funding from managed behavioral health care organizations, while preserving the values and operational independence of consumer-run services. Demonstrating effectiveness in reducing dependence on psychiatric hospitals and other cost-intensive care will help.

Rappaport, J. (1994). Narrative studies, personal stories, and identity transformation in the mutual-help context. In Powell, T. J. (ed), Understanding the self-help organization: Frameworks and findings (115-135), Thousand Oaks, CA: SAGE Publications.

Rappaport defines the self-help community as just that-- a community-- rather than an alternative to professional psychiatric care. Rappaport discusses the pitfalls of viewing self-help as an alternative treatment. More specifically, Rappaport discusses the GROW study and illustrates some of the limits of the alternative service model in his own work with several colleagues. Rappaport emphasizes the value of narrative stories of individual people as opposed to "professional centrism" (i.e., viewing professional groups as more helpful than self-help groups).

Participants in the GROW meetings are described as feeling a part of a caring community. They have come from being hospitalized to having hope and being givers as well as receivers. Likewise, individuals in GROW seem empowered in their ability to make positive change. These stories are presented along with "professional patient" stories in which individuals see themselves as sick and dependent on medication for behavior, as people who receive services and who have little to offer anyone else.

Rappaport goes on to discuss self-help organizations as normative narrative communities that should not be compared to professional treatment. For example, when participation in a self-help group leads to substantive change in an individual's behavior or identity, it could easily be understood as a change in lifestyle rather than as a "treatment outcome." People joining a self-help group are making a decision, which is empowering, as opposed to receiving services. Rappaport describes narrative studies and community narratives and personal stories, as well as narrative structure, function, and change.

He lists six reasons why the narrative viewpoint is appealing:

1. Everyone knows what a personal story is. It gives people an opportunity to discuss their subjective experiences of both stability and change.
2. Personal stories are powerful, make sense, and are persuasive.
3. Personal stories are a way of communicating and defining oneself. They respond to change over time.

4. Narratives are always being created and revised and the storytelling process is active.
5. Direct cross-level comparisons between individuals and groups occur because processes mirror themselves in the narratives.
6. The narrative way of analyzing has been pursued in many fields, such as psychology, psychiatry, and applied social psychology.

Rapping, E. (1998). There's self-help and then there's self-help: Women and the recovery movement. Perspective: A Mental Health Magazine, 1-6.

Rapping briefly speaks of the many women entering the 12-step movement and of how the 12-step movement has been taken up by professionals, TV talk shows, writers, etc. History helps us to understand both the appeal to women and the appeal to society at large. The feminist consciousness-raising model is described. Rapping believes that model was a bridge, for many women in the 80s and 90s, to the 12-step model.

The section "From CR to 12-Steps" suggests why women in the 80s and 90s have been so invaded by addictive disorders. Cuts in child care, health care, welfare, education, and job training have forced women to work a "double day." As a result, we have seen more women seeking chemical and non-chemical "highs." The author describes "an unsettling sense of having bought into being a world view that has now, through mass media, become the dominant view of emotional suffering, its causes and its 'cures,' in which the very possibility of thinking or acting politically has disappeared." Rapping goes on to discuss the enfeeblement of calling oneself "sick" and argues that we should work instead to change the societal illnesses that have led to so many women becoming addicted.

Riessman, F., (1990). The new self-help backlash. Social Policy, 43-48.

Riessman describes critics of self-help groups, particularly of Alcoholics Anonymous. Critics of AA especially criticize the way members "admit powerlessness" over the disease. Different points made by critics are discussed and answered. For example, critics claim that members of self-help groups are becoming addicted to the groups themselves. Riessman's response is that self-helpers going to more meetings does not make them junkies. Rather, it makes them less isolated and more able to find a positive source for growth. Recent criticisms of self-help that deserve thoughtful attention are that identity-based self-help groups need also to go beyond the personal and to look at the other, less individual roots of the problem (such as addiction). Such roots include poverty, racial tension, sexism, etc. The article also discusses false empowerment, i.e., consumers being led to believe they can deal with their health problems through self-help alone.

Segal, S. P., Silverman, C., and Temkin, T. (1995). Characteristics and service use of long-term members of self-help agencies for mental health clients. Psychiatric Services, 46, 269-274.

This study examined the characteristics of long-term members of self-help agencies managed and staffed by mental health clients, exploring why clients sought help from the agencies, and how they differed from clients of community mental health agencies. Surveys and other measures were used to find

information about the service use patterns of 310 long-term agency members, as well as about the members' resources, history of disability, functional status, psychological disability, health problems, and DSM-III-R diagnosis. Data from management information systems of the self-help and community mental health agencies were used to compare service populations. The self-help agencies served a mostly African-American population (64%), many of whom were homeless (46%). Eighty-seven percent had confirmed DSM-III-R diagnoses, and 50% had dual diagnoses with moderate to severe substance or alcohol dependence. They had sought help from the self-help agencies mainly for food or clothing, for a place to be, or because they were homeless. Finding counseling or help for substance or alcohol abuse was a less important reason for coming to the self-help agencies. A high proportion of the persons served by the self-help agencies in the study were homeless and had a dual diagnosis of mental disorder and substance abuse. The self-help agencies provided their clients with material resources while community mental health agencies provided therapy and medical care.

The self-help centers the authors studied were concerned with improving members' lives and helping them gain skills and resources to achieve stability, but the centers also place the responsibility to make the necessary changes on the members themselves. At the same time, the agencies believe that societal problems and injustices contribute to members' problems and that these injustices must be changed through people taking action together. The survey was conducted in 1992 to 1993 in the San Francisco Bay Area. The mean client age was 37 and the median age was 38. Forty-six percent were actually homeless at present. In addition, 78% had been homeless at least once in the past five years, often for long periods. Eighty-seven percent of the respondents had been diagnosed with an illness in DSM-III-R. Half of the respondents had a dual diagnosis of mental illness and substance abuse. 98% had held jobs in the past, but only 24% did so at the time of the interview. Thirty-six percent received Supplemental Security Income or Social Security Disability Income and 36% received general assistance. 87% of respondents had experienced at least one of 16 major stressors in the past year. Stressors included being thrown out of or losing a place to stay, losing a job, spending time in jail or prison, grieving for the death of someone close, etc. Forty-six percent were referred by family or friends; one-fifth were referred by a mental health or social service agency; 20% heard about the agency by word of mouth on the street; and 10% happened to be walking by. Referrals included requests for food (26.3%), bus pass (28.5%), place to shower (21.2%), clothing (36.9%), mailing address (42.3%), personal items (18.6%), temporary housing (34.3%), supported employment (22%), and services information (38.8%). Users of the two agencies were compared. The self-help agencies are able to attract and serve exactly the group of people they claim to serve and are intended to serve. The populations served by the self-help agencies and by the clinics operated by the community mental health agency overlap - 28% of these respondents were receiving counseling, and another 26% had done so in the past. This information suggests that self-help agencies, in combination with community mental health agencies, can serve a poor, mostly African-American, and often homeless population -- subgroups that are traditionally not well served by the mental health system.

Segal, S. P., Silverman, C., and Temkin, T. (1995). Measuring empowerment in client-run self-help agencies. Community Mental Health Journal, 31, 215-227.

In their abstract, Segal, Silverman, and Temkin state, "'Empowerment' connotes a process of gaining control over one's life and influencing the organizational and

societal structures in which one lives. This study defines and validates three measures: the Personal Empowerment Scale, the Organizational Empowerment Scale, and the Extra-Organizational Empowerment Scale. Measurement efforts are based on observational work, baseline interviews with a sample of 310, and six month follow-ups with a sample of 241 in four client-run self-help agencies for persons with severe mental disabilities. All three study scales demonstrated strong internal consistency and stability. They were sensitive to user changes over time and have construct validity."

Segal, et al. discuss the meaning of empowerment in self-help agencies. Programs run by mental health consumers/survivors empower people because the contact with and reliance on peers encourages this grass-roots process. Essential characteristics of self-help agencies include client control of all program aspects, with independence from the mental health system; completely voluntary services; sharing of power within a structure that tries to avoid hierarchical relationships; and emphasis on addressing the economic, cultural, and social needs of members. Self-helpers see empowerment as related to self-efficacy, self-esteem, and the sense that positive personal change can come about through one's own efforts. Empowerment within an organizational or societal context, then, is seen as encouraging empowerment both in one's personal life and in the larger community.

Four self-help agencies in the San Francisco Bay Area were observed over a 12-month period. Baseline and six-month follow-up interviews were given. Three-hundred and ten people completed the baseline interview with 248 (80%) completing the follow-up. The different scales used are given in the abstract. The people who were included showed stability and consistency over the 12 months in the following areas:

1) Direct Empowerment Measures

- a. Personal empowerment
- b. Organizational empowerment
 - a. Extra-organizational empowerment

2) Related Empowerment Concepts

- a. Self esteem
- b. Hope
- c. Internal locus of control
- d. Self efficacy

3) Functional outcomes

- a. Quality of life
- b. Independent social functioning

Self-efficacy, self-esteem, and internal locus of control have the highest convergent correlation. According to the study, organizational and extra-organizational empowerment measures depend more on involvement in the work role, while personal empowerment is more related to general independent social activity. Conclusions of the study are that empowerment is complex; the different areas of empowerment are related to different outcome domains, such as

personal empowerment and extra-organizational empowerment; and self-efficacy is the bridge between the two main areas of empowerment.

Silverman, S. and Hamilton, H. Evaluation of an Alternative, Innovative Consumer-Run Model of Service Delivery: A Study of 'On Our Own, Charlottesville, Virginia': The Drop-In Center. Unpublished manuscript.

In their abstract, Silverman and Hamilton state, "Research on self-help for consumers of mental health services has traditionally focused on the operation of voluntary groups, such as AA, Mental Health Associations, etc., and has generally ignored service programs operated by consumers. This evaluation study focused on the only consumer-run program in the Commonwealth of Virginia, established three years ago in Charlottesville. The center serves a population of seriously mentally ill, homeless, and individuals with a history of substance abuse. The center is a private, non-profit, tax-exempt organization begun by consumers with a grant from the Virginia Department of Housing and Community Development, granted through the McKinney Act to serve the homeless. Now in its third year, though receiving financial support from state sources, the program remains true to its original ideals -- an all-consumer staffed service organization. Structured interviews of consumer-users of this program indicated that the program was meeting its funding intents of providing services for individuals either seriously mentally ill or homeless, by creating an environment that promotes social support and shared problem solving. The level of satisfaction with programs and environment was relatively high. Issues which have emerged for future research include providing additional services for a dually-diagnosed population that may require more structure, establishing additional funding sources, and determining the long-term benefits of Drop-In Center participation."

The paper provides a brief literature review. The study asks whether the values of a consumer program are being met and whether the members of this Center are the targeted population of mental health consumers presently being served by the traditional, publicly funded system. Data were collected over six weeks by four graduate students who were not complete strangers to members of the Drop-In Center. It was made clear that interviewers had no personal stake in interviewee responses. Administration of each interview lasted 30 to 60 minutes. A brief demographic questionnaire was given, followed by the Degogatis' Symptom Inventory and Moos' COPES scale. The sample size was 24 members. The article gave demographics. The symptom scale was highest for the obsessive compulsive scale and the paranoia scale. The results of the COPES survey showed that on all three dimensions (relationship, personal development, and system maintenance and change), combined scores point to a very successful program. The strength of the program appeared to be on the dimension of relationship. The mean differences observed in the other two dimensions of the COPES, personal growth and system maintenance, show there is room for growth in program offerings. Increased training among consumer staff who provide peer support may be needed. Demographic data indicate that the people benefiting from the Center are mainly the target population: mental health consumers, the majority of whom have histories of hospitalization.

Snowden, L. R. and Lieberman, M. A. (1994). African-American participation in self-help groups. In Powell, T. J. (ed), Understanding the self-help organization: Frameworks and findings. (50-61). Thousand Oaks, CA: SAGE Publications.

This chapter reviews the literature regarding African-American participation in the self-help movement. There has been long-term involvement in civil and fraternal organizations, but African-Americans have had little perceived involvement in one-on-one participation in mental or physical self-help. Among surveys inquiring into self-help use, only the Epidemiology Catchment Area (ECA) obtained a significant number of African-American respondents. The reason for that significance appears to be the size of the ECA sample and the over-sampling of African-Americans. The authors studied the ECA statistics and compared African-Americans to Latinos/Latinas and Caucasians. Data from the California Self-Help Center were also examined.

The ECA data were collected at New Haven (Connecticut), Baltimore, St. Louis, North Carolina, and Los Angeles. The ECA study told what percentages of the catchment areas were African-American. All together 4,300 African-Americans were surveyed and 12,152 Caucasians were surveyed. The California study has an active file of 4,000 self-help groups. The file contains items such as characteristics of participants and other variables. Over a lifetime, approximately 3.6% Caucasians and approximately 1.1% African-Americans reported having used self-help groups. The chapter describes statistical methods finding that ethnicity and social class were independent factors connected to use of professional mental health, as well as self-help group services. African-Americans were compared to Caucasians and Latinos/Latinas to report self-help group usage. According to the results of the statistics, African-Americans use self-help groups at an especially low level. Likewise, African-Americans, when compared to Caucasians, with a DSM-III diagnosis were found to use self-help groups at an especially low level. There was no evidence that African-Americans use religious leaders or alternative healers instead of using self-help groups.

In the California Self-Help Center report, the total membership of the groups was 373,000. The African-American membership was .4% and the African-American population of California was 7.4%. Recommendations are made for improving the ECA study, as well as the California Self-Help Center study. Education and community awareness of self-help groups are important, and groups should be geared more to the ethnic needs of the African-American community.

Solomon, P. (1994). Response to "Consumers as service providers: The promise and challenge." Community Mental Health Journal, 30, 631-634.

This article was written as a response to the article above by Dixon, Krauss, and Lehman. According to Solomon, the other article clearly shows the value of consumers as members of a multi-disciplinary team. However, Solomon points out, the consumer has not been accepted as a full fledged member of the team, but rather has been placed in a gray area between the service providers and the clients or patients. A clear role has been lacking, which leads to difficulties in implementing programs. Difficult issues include role responsibilities, boundary relationships, and supervision and support. According to Solomon, Dixon, Krauss, and Lehman describe staff as uncertain about what strengths consumers in general might have and as therefore permitting the job to be defined by the individual strengths of consumers filling it. The resulting problems cannot be explained as problems caused by filling the position with a consumer. Solomon questions why the consumer did not fill one of the case management positions, since significant contributions of the consumer advocate are characteristics of a good case manager. Case management is basically a service coordination job, which is ideal for consumers. She recommends substituting "life experience" for educational requirements. Solomon indicates that in the article she is responding

to, the consumer advocate position was poorly defined and that the consumer advocate seemed to share many of the responsibilities of the case manager, which undoubtedly would result in some role conflict with the case managers.

According to the author, the ACT approach gives programs a chance to hire consumers as case managers, because it allows for services to be provided by other case managers in potential periods of illness and for the consumer case manager to hold a smaller caseload until she or he is properly trained. Both of these are reasonable accommodations under the Americans with Disabilities Act. An advantage of having consumers fill the position of case manager is that consumers could then bill for services. Mental health professionals must also recognize that not all mental health consumers will want to accept a job as a "professional consumer." The author cautions against putting another label on them and stresses the need to have more than one consumer on the team. She concludes that it is time to move beyond "professional consumerism" to real jobs for mental health consumers.

Solomon, P. and Draine, J. (1994). Family perceptions of consumers as case managers. Community Mental Health Journal, 30, 165-176.

In their abstract the authors state, "Family members of clients participating in a randomized trial of consumer delivered case management services were found to be satisfied with the services, without regard to whether or not their ill relative was served by a consumer case management team. While family members did not necessarily know that their ill relative's case manager was a consumer, the attitude toward the capabilities of consumers serving as case managers was positive."

With deinstitutionalization, families have been expected to take more responsibility for their relatives with mental illness. Despite the added responsibility, families have not been given credit for all they are doing and at times have been blamed for their relative's disability. Families have often felt left out of the treatment process and dissatisfied with services. However, one area that has received a more positive review by families is case management services. As there has been increasing value placed on the views and contributions of families, so there has been increasing respect for what consumers have to offer. This study, which was conducted as part of a larger study, was designed to assess families' satisfaction with services received by their disabled relative from either a team of consumer case managers or a team of non-consumer case managers. Ninety-four clients identified a family member to be interviewed. A total of 55 family members were interviewed either by phone or in-person. Twenty-three of their relatives were served by the consumer team and 32 by the non-consumer team. The interviews were conducted at the 18-month point and included demographic information and satisfaction questions regarding services for both their disabled relatives and themselves. Family members were also asked questions concerning the qualifications of their relative's case manager and whether the family members would have any concerns if the case manager had experienced a mental illness him/herself. Initially, descriptive statistical studies were conducted. Subsequently t-tests and chi squares were used to determine whether there were differences in satisfaction for those whose relatives were served by the consumer and those whose relatives were served by the non-consumer team of case managers. Due to multiple tests of significance, a Bonferroni adjustment was used.

The sample of family members was mostly female (82%), with a mean age of 51 and an age range of 28 to 85. The majority were black (86%), with 11% white, 1 Hispanic, and 1 Native American. The average monthly income was \$1137.63. Only 25% had less than a high school education. Forty-two per cent were currently working full time. In the client sample, 56% were male, most were black (86%), and most were never married (61%). The mean age was 40 with a range of 20 to 75. Almost three-quarters were on SSI/SSDI. Most (85%) were diagnosed with schizophrenia and almost all had had a prior hospitalization.

Family members with ill relatives who received case management from either a consumer or non-consumer team were highly satisfied with the service. The only area in which there was a difference in the views of families whose relatives received services from consumers was in the testing and monitoring of medication. When asked their opinion of the possibility of consumers serving as case managers, few family members gave negative responses. Families seemed more concerned with a possible change in case manager, regardless of which team served their relatives. There was no difference in symptomatology, or in clinical and quality of life outcomes of clients served by the consumer team. The authors caution that these results should not be used as support for employing consumer case managers as a cost-saving strategy. Consumers should be employed because they can do the job.

Solomon, P. and Draine, J. (1994). Satisfaction with mental health treatment in a randomized trial of consumer case management. The Journal of Nervous and Mental Disease, 182, 179-183.

In the abstract, Solomon and Draine state, "It was hypothesized that the clients assigned to a consumer team of case managers, because they share similar life experiences interacting with the mental health system, would have greater satisfaction with mental health treatment than clients assigned to a team of non-consumer case managers. Ninety-one clients with serious and persistent mental illness randomly assigned to consumer and non-consumer case management teams were interviewed after one year of service. While clients served by a consumer team of case managers were less satisfied with mental health treatment, personal characteristics of individual case managers were more important in explaining differences in satisfaction with treatment than whether the client was served by the consumer or non-consumer team."

Ninety-six persons were recruited and assigned to one of two case management teams - either consumer or non-consumer. At baseline, demographic and clinical data were taken from the information system of the agency. Clients were interviewed about a month after they were assigned to a case management team and again one year later. A 16-item scale was constructed to measure satisfaction with mental health treatment throughout the service year. Clients were also asked to assess whether their case managers were helpful in a variety of case management functions.

Ninety-one of the original 94 participants in the project were interviewed one year later. Forty-six of the consumer case management clients and 45 of the non-consumer case management clients were interviewed. The average satisfaction score for clients served by the consumer team was 2.78 and the average satisfaction score for clients served by the non-consumer team was 3.10. Clients who perceived their case managers as understanding, caring, able to comfort, etc., were more satisfied with mental health services. It appeared that the characteristics of individual case managers and the more general elements of the working alliance were more important in explaining the differences in overall

satisfaction with mental health treatment than whether the clients were served by a team of consumers or non-consumers.

Solomon, P. and Draine, J. (1996). Perspectives concerning consumers as case managers. Community Mental Health Journal, 32, 41-46.

Solomon and Draine state "consumer and non-consumer case managers participating in a randomized trial of consumer case management were interviewed regarding their perceptions of consumer and non-consumer case managers, their work and their clients. Consumer case managers were concerned about how they were accepted by other mental health professionals. The consumer team maintained less collateral contact with other professionals and more interpersonal contact with clients than the non-consumer team did. Consumer case managers did not show any greater signs of stress, diminished self esteem, or burnout than non-consumer case managers."

Ninety-six clients were randomly assigned to a team of consumer case managers operating in a consumer self-help organization or to a team of case managers operating as a service of a community mental health agency. In addition to usual employment requirements, the consumer case managers also had to meet criteria related to their mental illness. Case managers were interviewed at the beginning of the study, at six months, and at one year, individually and as teams, on several occasions. Both teams were approximately 50% male and 50% female. The consumer team tended to have more representation of minority groups, to be older, and to have a wider range of educational backgrounds. The majority in both teams had previously worked with persons with severe mental disabilities.

Consumer case managers did not have the usual clinical supports available to non-consumer case managers. The authors suggest mental health centers hire consumers as case managers and offer clinical support. Both case management teams were only somewhat likely to seek alternatives to mental health system service resources, and the consumer team did not show any more likelihood to do so than the non-consumer team. Case managers also had concerns about the acceptance of clients by non-mental health services. Case managers may need more training and direction in how to connect with community resources rather than depending on the mental health system for all client service needs. Functioning as a team proved difficult for both teams. Regardless of consumer or non-consumer status, case managers were more comfortable working individually with their clients than sharing responsibility with other team members. The characteristics and personalities of individual case managers appeared to be at least as important as their consumer/non-consumer status in influencing the case management relationship. Consumer case managers, however, tended to see their clients as somewhat less capable. This could be because of the youth and inexperience of the non-consumer team in the mental health system, or to an unusually high level of expectation from consumers who had achieved professional status while overcoming the stigma of mental illness. The main limitation of this study was its small sample size.

Stephens, C. L. and Belisle, K. C. (1993). The "consumer-as-provider" initiative. The Journal of Mental Health Administration, 20, 178-182.

According to the abstract, "The National Institute of Mental Health has provided funding in Region I (New England) to several technical assistance centers: the Center for Community Change through Housing and Supports (Vt.); the Human

Resource Association of the Northeast (Mass.); and the recently funded National Empowerment Center (Mass.). These federally funded projects are focused on guiding the mental health field toward a more consumer-driven system. The authors have been involved with these organizations and also provide consultation along with Northern Rhode Island Community Mental Health Center (NRICMHC) staff and consumers to other counties and states on improving services for adults and children with longer-term psychiatric problems. The consulting team for NRICMHC has encountered some communities where the hiring of current or former consumers appeared to present a 'quick fix' for system problems rather than a reflection of more basic changes in attitudes and programs. Based on the authors' personal and family experiences, as well as their work experiences, they have re-examined some of the conventional wisdom in the rapidly evolving area of 'consumers as providers.'"

There is a risk that moving consumers toward being providers will support and continue myths, mistakes, and false distinctions that make the humanizing, normalizing, integrating, and reforming of community mental health services more difficult. The article reviews nine conventional wisdoms and provides alternatives to each. For example, a conventional wisdom is that agencies must hire "consumer providers" because it is commonly believed that administrators and providers of services have never been mental health consumers. The alternative belief is that agencies with a clear commitment to persons with severe or persistent mental illness will attract and keep a significant number of former and current consumers in their work force. Consumer services are strongest in agencies that evaluate applicants not only for their personal and professional experiences, but for their values, helping, advocacy skills, and openness to growth and learning. Mental health competencies are not automatically established by either an academic degree or a psychiatric hospitalization. The nine conventional wisdoms bring with them potentially damaging policies. Rigidity in the definition of a consumer may promote further division and competition within the mental health system, among parties who already hold less power, status, and resources than are needed to maintain a community-based, rights-oriented system of care. There are six principles that the mental health force and systems should consider if they are to be inclusive and consumer-driven. One is that a broad-based affirmative-action plan can be of greater value to all consumers and providers than a focused consumer-as-provider initiative.

Surles, R. C. (1994). Can client outcomes be enhanced by integrating consumer peer specialists into intensive case management teams? Evaluation Bulletin: New York State Office of Mental Health, 2, No. 1.

A growing number of mental health programs across the country are experimenting with employing mental health consumers as service providers. This research design allows for direct comparisons of outcomes for clients of the experimental consumer-professional model with outcomes for clients serviced by the pre-existing professional-only model. In addition, a third comparison group was included: professional case managers plus non-consumer paraprofessional workers, a group that allowed assessment of the effects of simply adding staff.

Complete longitudinal data were collected for 104 clients, 61% of the 170 who agreed to participate in the research. A repeated measures analysis of variance model was used to compare outcomes among the three client groups. Overall, the results indicated a significant relationship between client outcomes and treatment condition for six measures. There was little evidence that the addition of non-consumer paraprofessionals resulted in improved client outcomes beyond

those associated with regular ICM. There was strong evidence that integrating recovering consumers into ICM teams was associated with enhanced service effectiveness. Consumer-providers appear to bring unique characteristics and contributions to the mental health workplace.

Van Tosh, L and del Vecchio, P. (1998). Consumer/Survivor-Operated Self-Help Programs: A Technical Report. Unpublished manuscript.

In light of the possible contribution self-help can make to the recovery process, to cost-effectiveness, and to the success of related fields, such as substance abuse, the Community Support Program (CSP) began to support various technical assistance initiatives to promote self-help. Jacqueline Parrish, a CSP staff member, led this promotion, in which manuals were developed, newsletters published, and drop-in centers started. New grant announcements were issued in 1988. The professional community was beginning to realize that mental health consumers should take an active role in treatment and that client-operated services were able to reach those who declined help from the formal mental health system. There were other good reasons for starting consumer-operated projects. The 13 projects demonstrated a variety of services and supports, including peer supports, consumer-operated businesses, and community education. These demonstration projects have been among the most important and innovative supported by CSP.

The technical report by Van Tosh and del Vecchio includes three chapters. Chapter One reviews the consumer/survivor self-help movement; Chapter Two discusses various consumer/survivor-operated self-help programs; and Chapter Three discusses cross-site findings and recommendations.

Chapter One introduces the National Institute of Mental Health's Community Support Program, discusses methodology, and offers a literature review. An examination of the findings of these innovative consumer-operated services demonstration projects was conducted. A cross-project analysis found similarities and differences, made observations, and recommended ways to set up, operate, and evaluate consumer/survivor-run programs. A literature review of self-help programs, including over 80 pieces of literature, gives a brief history of the self-help movement and some background information, along with a definition of self-help. The chapter describes Alcoholics Anonymous, and the benefits and characteristics of self-help. The chapter goes on to describe the mental health consumer movement. Outside support for and benefits of consumer/survivor self-help are discussed, along with valuable and unique features of consumer/survivor self-help. Consumer/survivor self-help classifications are given. Funding, impact of the consumer/survivor self-help movement, and consumers/survivors as colleagues are also addressed. Evolution of mental health consumer/survivor-operated self-help programs is reviewed at length. Subtopics are history of consumer/survivor-operated programs; types of services offered; structure and organization of consumer/survivor-operated self-help programs; funding; program administration and leadership; staffing; populations served; program governance; research and evaluation; and interaction with other agencies.

Chapter Two describes 13 demonstration projects. It includes sites from California, Colorado, Indiana, Maine, Missouri, New Hampshire, New York, Oregon, Tennessee, Vermont, Washington, West Virginia, and Wisconsin. Documents reviewed from each project include original applications, annual continuation applications, related correspondence, final project reports, and

evaluation findings. The following parts of the program are discussed: project goals; services and supports provided; client population served; organization of staff and other people involved with the program; board development; staff size, characteristics and training provided; reasonable accommodation practices; program materials developed; implementation issues; inter-organizational coordination; existence of other self-help programs before and after the demonstration grant; project budget; evaluation strategies and findings; and program continuation plans. This information may be skewed because it comes from self-reports created by the projects. Other materials were prepared by the State mental health authority personnel, who are not familiar with the day-to-day operations of the centers, which also may compromise validity. However, the study of the projects is still valuable.

Chapter Three describes cross-site findings and recommendations. The authors point out some methodological weaknesses with this approach. For example, since different service models were developed in very different environments, there is the chance that many outside factors may have changed the site and cross-site findings. Data are limited in their comprehensiveness and validity. Significant similarities and differences are presented in the following domains:

- 1) Project goals
- 2) Services provided
- 3) Individuals served
- 4) Organization and administration
- 5) Implementation issues and barriers
- 6) Successes and evaluation findings
- 7) Recommendations

The recommendations call for increased technical assistance and training, better planning, adequate funding and continuation, enhanced cooperation, expanded people-of-color representation, more research, and direct funding of projects. The summary emphasizes the need for more research about cost/benefit analysis, independence, the impact of self-help on specific sub-populations, recipient satisfaction with services, empowerment, and examining whether these programs serve those whose needs would not otherwise be met. The report calls for consumer/survivor involvement in every stage of the research process.

Van Tosh, L. (with Finkle, M., Hartman, B., Lewis, C., Plumlee, L., and Susko, M. A.). (1993). Working for a change: Employment of consumers/survivors in the design and provision of services for persons who are homeless and mentally disabled. Center for Mental Health Services, 1-27.

This 27-page document contains an Introduction, followed by sections entitled People Helping People, The Evolution of Mental Health Consumer/Survivor Participation in Providing Services, Emerging Employment Trends, Qualities of Mental Health Consumers/Survivors Working in the Areas of Mental Health and Homelessness, Descriptions of Roles of Mental Health Consumers/Survivors in

Providing Services, Unique Issues of Mental Health Consumer/Survivors in Participating in the Provision of Services, Recommendations, References, and an Appendix of Workgroup Participants' Biographies. According to the author, this report represents the efforts of a group of current and past consumers of mental health services who explain the importance of consumer involvement in the design and delivery of services to persons with mental illness and homelessness. The report arises from a research demonstration project funded by the Center for Mental Health Services to develop and evaluate innovative service programs for persons who are homeless and mentally disabled. This author identifies the qualities and unique issues of consumer/survivor participation in the planning, delivery, and evaluation of services for persons who are homeless and mentally disabled. Major employment trends that contribute to the increasing participation of consumers/survivors in these areas are discussed. Issues that may affect future programs and initiatives designed to employ consumers are also explored. Finally, recommendations are made about the mental health system and the consumer/survivor/mental health self-help movement's attempts to keep developing good ways to help persons who are homeless and mentally disabled. This paper was thought about, organized, and written by consumer/survivors.

The People Helping People section discusses the self-help, consumer/survivor movement and issues that are especially important to it. The Evolution of Mental Health Consumer/Survivor Participation in Providing Services discusses the history of the mental health self-help movement as well as consumer/survivor-operated programs and other services for persons who are homeless and mentally disabled. Emerging Employment Trends discusses a sampling of trends that are emerging in the areas of mental health and homelessness. For example, the major social problems of homelessness and the increasing lack of decent, affordable housing and employment opportunities for persons who are homeless and mentally disabled highlight the need for more workers who are creative and dedicated to ending homelessness and poverty. In the section Qualities of Mental Health Consumer/Survivors Working in the Areas of Mental Health and Homelessness, unique characteristics, which make consumers/survivors' especially suited to serve individuals who are homeless and have a mental disability, are discussed. Some of the characteristics include "systems knowledge" (how to get around within the network of people and organizations offering service), street-smarts, flexibility, and patience. Descriptions of Roles of Consumers/Survivors in Providing Services lists numerous roles in several service areas. For example, in-program planning and design job developer, program coordinator/director, housing developer, fund raiser, planner, and researcher are listed. In the section Unique Issues of Mental Health Consumers/Survivors Participating in the Provision of Services, numerous issues, such as professionalism, federal Social Security Insurance, stigmatization, and ability to sympathize, are discussed. Recommendations are made in the areas of job supports, education and training, recruitment issues, policy issues, and research. The author recognizes that consumers/survivors' talent, diversity of opinion, and creativity have propelled the mental health self-help movement into several national debates and forums. The doors to involvement, participation, and development have begun to open.

White, B. J. and Madara, E. J. (eds). (1998). The self-help sourcebook: Your guide to community and online support groups. (Sixth edition). Denville, NJ: American Self-Help Clearinghouse.

This sourcebook is published every two years and has been used by many people who have diverse interests and who are looking for a group to meet their

special needs. Alfred H. Katz states in the forward that this book does more than merely provide accurate information. The book marks a growing acceptance of the social movement of self-help groups.

An introductory section discusses how to use the sourcebook, how to find a group, how to form a group, and things you should know when contacting any group by phone or mail. This section also discusses the American and New Jersey Clearinghouses.

Chapter One introduces self-help groups and defines the term "self-help group." A section follows on understanding what self-help groups do and how they do it. This chapter also lists ten good ways to interact with a self-help group and ends with a list of writings by professionals about self-help.

Chapter Two discusses starting a group and makes suggestions about how to do that. Then it gives a guide for the group contact person, and ends with ten steps and suggestions for professionals.

Chapter Three discusses the internet and how to find groups on it, the commercial computer systems, the value of online groups, and other ways the internet may be helpful.

Chapter Four recommends that before trying to start an online group you find out if an online resource on your topic is already available. This chapter discusses figuring out what you want to create on the internet and then creating it.

Chapter Five provides research reviews of mental health groups, weight-loss groups, addiction-related groups, bereavement groups, diabetes groups, caregivers groups, cancer groups, and chronic-illness groups.

Chapter Six lists clearinghouses in the United States and numerous other countries.

Chapter Seven lists self-help groups in different special need areas, such as abuse, addictions, bereavement, disabilities, family, health, and mental health.

Chapter Eight gives specialty toll-free phone numbers.

Zinman, S. (1987). Definition of self-help groups. In Budd, S., Harp, H. T., and Zinman, S. (eds), Reaching across: Mental health clients helping each other, Riverside, CA: California Network of Mental Health Clients.

Zinman defines self-help groups as having sprung from and as being important to the "mental patient" liberation movement. She writes about freeing "mental patients" from their/our externalized and internalized bonds, of freeing ourselves from the stigmatized images of culture, family, and the "mental health system."

The essential characteristics of self-help groups are to be self-defined and client-controlled; to be totally voluntary and based on self-determination; to share power, responsibility and skill; and finally to treat people as people and not as diagnoses or labels. Self-help groups are effective because they allow us to learn

control over our lives; to restore power and hope to clients; to offer spiritual and physical support; and to provide us with the tools to help ourselves. Self-help groups can be very different from each other and include support groups, independent living programs, drop-in/advocacy/independent living services, political action groups, client-run housing, self-supporting businesses, and theater groups. Zinman also addresses the bond between political action and services/support groups, noting that political action groups are very goal-oriented and lack the mutual-help services that support groups usually offer.